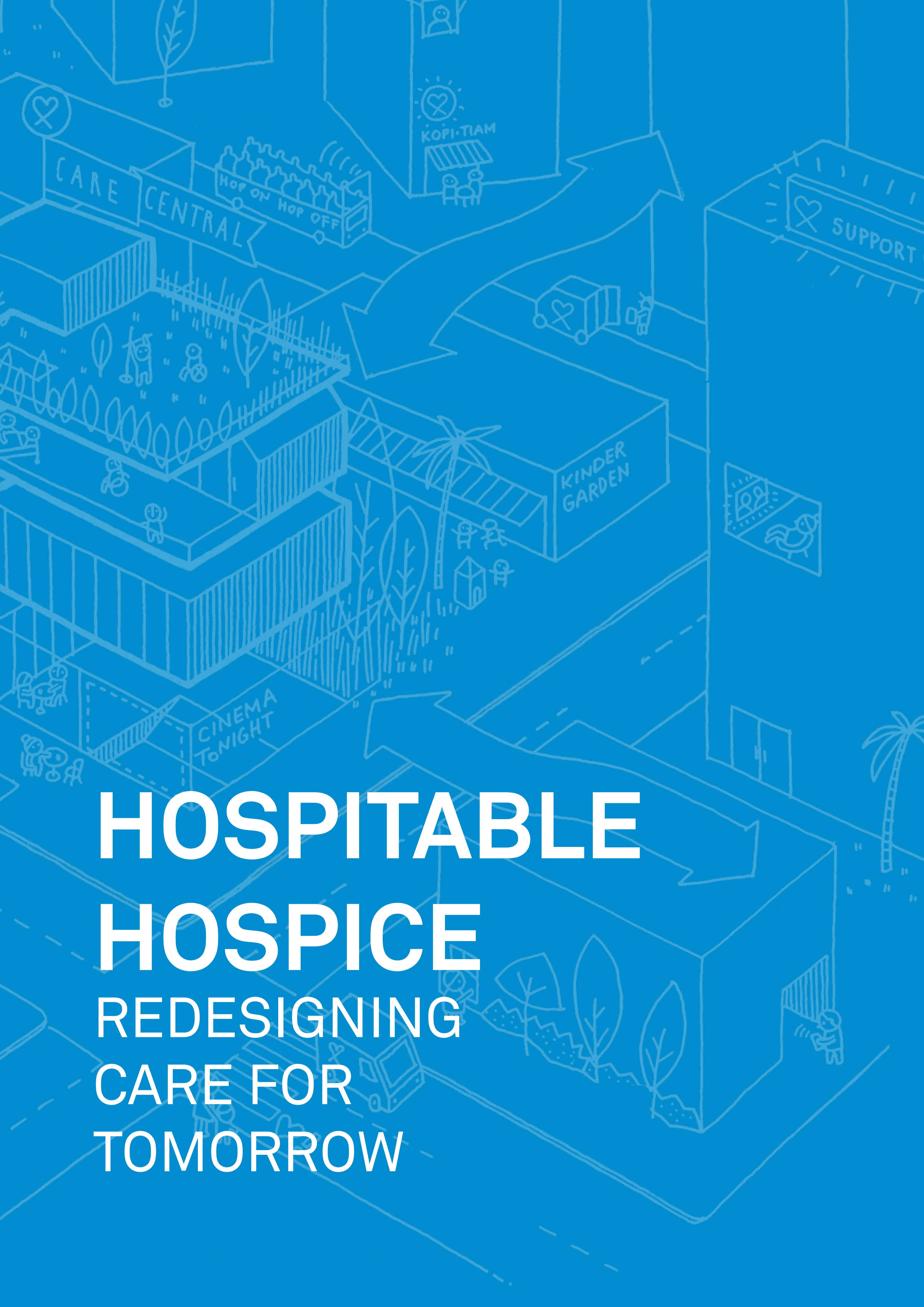

HOSPITABLE HOSPICE

REDESIGNING CARE FOR TOMORROW

Commissioned by

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fuel for
Lien Foundation &
ACM Foundation

CONTENTS

WHAT IS THIS BOOK?

(AND WHAT IT IS NOT...)

This hand book is...

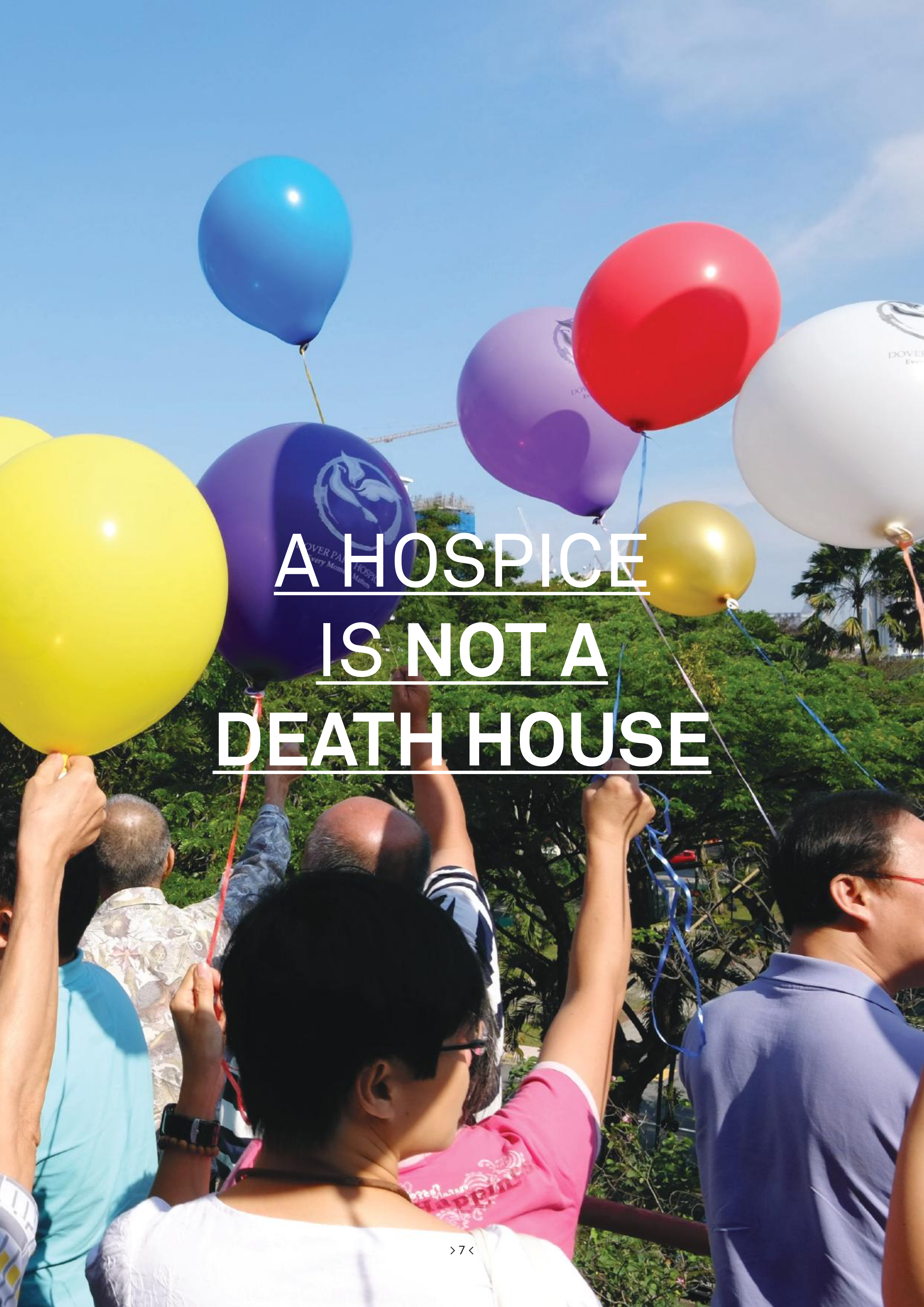
- to inspire you to design tomorrow´s hospice service experience, starting today.
- based on the Singapore context, but contains insights and ideas that can be considered universally relevant.
- a guide to understanding what hospice care is today in SIngapore - its characteristics, challenges and aspirations as an essential service within the context of end-of-life care.
- informed by in-depth insights gathered directly from patients, hospice care teams and families, as well as local domain experts and international best practice case studies related to hospice care.
- advocating 24 hospice experience design principles that can be used flexibly to create viable service experiences that your patients, care teams, families and communities can find meaningful.
- illustrative of these principles-in-action, presenting a set of visualised concept maps that suggest seven ways to redesign the hospice service experience.
- an invitation to rethink how hospice care should be - use it as a conversation starter with a colleague, as a means of articulating and sharing your own vision with partners, as inspiration to define your own projects, as an advocacy tool to lobby for the changes you believe in.

This book is not meant to be...

- a detailed design specification for the future hospice, because one design does not fit all.
- only for designers or architects, but for multidisciplinary teams that also include clinicians, nurses, social workers, therapists, administrators, volunteers, planners - in fact anyone working to design better hospice services.


DOVER PARK HOSPICE
Every Moment Matters

A HOSPICE IS NOT A DEATH HOUSE



A HOSPICE IS NOT A HOSPITAL

A HOSPICE IS NOT JUST FOR PATIENTS


MICHELLE POH

A HOSPICE IS NOT A DEPRESSING PLACE TO WORK

A HOSPICE IS NOT TO BE FEARED

FOREWORD

By Lee Poh Wah, Lien Foundation & Ang Ziqian, ACM Foundation

Reaching the end of life can be a messy affair. The exit lines mired in countless decisions and difficult conversations. Hospices, where care aims to help people die comfortably, have alleviated pain, provided emotional and psychological support, and turned last days into fitting finales. Yet, for the wonderful work they do, many hospices suffer a poor image that begs change. They deserve better understanding from society and fresh insights to empower them for the future.

With these challenges in mind, the Lien Foundation and ACM Foundation commissioned a project to redesign in-patient hospices for the future. The two Foundations share a common interest to expand the boundaries of end-of-life care and improve care for the dying.

Growing demands on healthcare and aging demographics makes it necessary to evolve fresh perspectives in hospice care. Design thinking has successfully improved various aspects of healthcare in different parts of the world. Hence, we tasked fuelfor, a design consultancy specialising in healthcare, to apply a design thinking approach to the hospice experience from the perspective of patients, families and palliative care professionals.

Over nine months, fuelfor delved into the hospice sector in Singapore conducting workshops and extensive interviews of various experts and stakeholders, including the project's partners – Assisi Hospice, Dover Park Hospice and St Joseph's Home and Hospice. The results offer new thinking and vision for the hospice movement.

Within this handbook are seven key universal design concepts that address the future hospice experience at multiple levels - policy, facility, community and the individual. The 24 design principles present core ingredients to shift paradigms - like transforming the hospice from being a place of isolation to being engaged in community, from being just another institution of care to becoming a source of personalised care, and from offering only end-of-life services to extending after death care.

We hope there will be a rise of the "hospitable hospice" - where the spirit of hospitality and care permeates - from its physical design and environment to work processes and delivery of care. A hospitable hospice is human centered, patient-oriented and staff-friendly.

We recognise that the end-of-life brings its own very special challenges and opportunities to create the very best environment possible in honour of patients and their families. This is a formidable task that our partner hospices, industry experts and the fuelfor team have sought to achieve. We wish to specially thank them for their time, valuable input, incisive analysis and recommendations.

We hope this report will spark a new trajectory of hospice care and best practices, and with design thinking, evolve the hospice into an essential, unequivocal and welcomed part of life services.

KEY ISSUES

Decision-making is highly stressful for patients/families

Still living while dying

Hospice is isolated from society

Hospice spaces are not designed to support palliative care practices

Hospice & funeral services are negatively perceived

Death is a taboo subject

Lack of understanding about palliative care

Loved ones need ongoing support

Existing funding sources cannot serve rising demand

Lack of personalisation

Inconsistent service experience

Discontinuous information flow

Palliative care teams need to be cared for

Shortage of palliative care professionals

TODAY´S HOSPICE IS...

Invisible and **isolated**, causing further **fear** and **misunderstanding** about its role and service to society.

Under resourced with right professionals, technologies and environments.

Inspiring in its ability to attract committed and compassionate care givers who try to facilitate life-affirming, dignified and personalised deaths in spite of the above challenges.

Located within a fragmented end-of-life care landscape, with services **scattered** across separate **standalone** settings.

Bureaucratically **dense** with processes that make care pathways and case management **complex, messy and stressful** for patients, loved ones as well as providers.

Unsustainable and **ill-equipped** to face the rising demand from an increasingly old and chronically sick population.

An **essential** palliative care service for every society.

TOMORROW´S HOSPICE SHOULD BE...

Supporting loved ones in **navigating** the end-of-life journey with **confidence and ease.**

Enabling communities to play an **active role**, participating in end-of-life care.

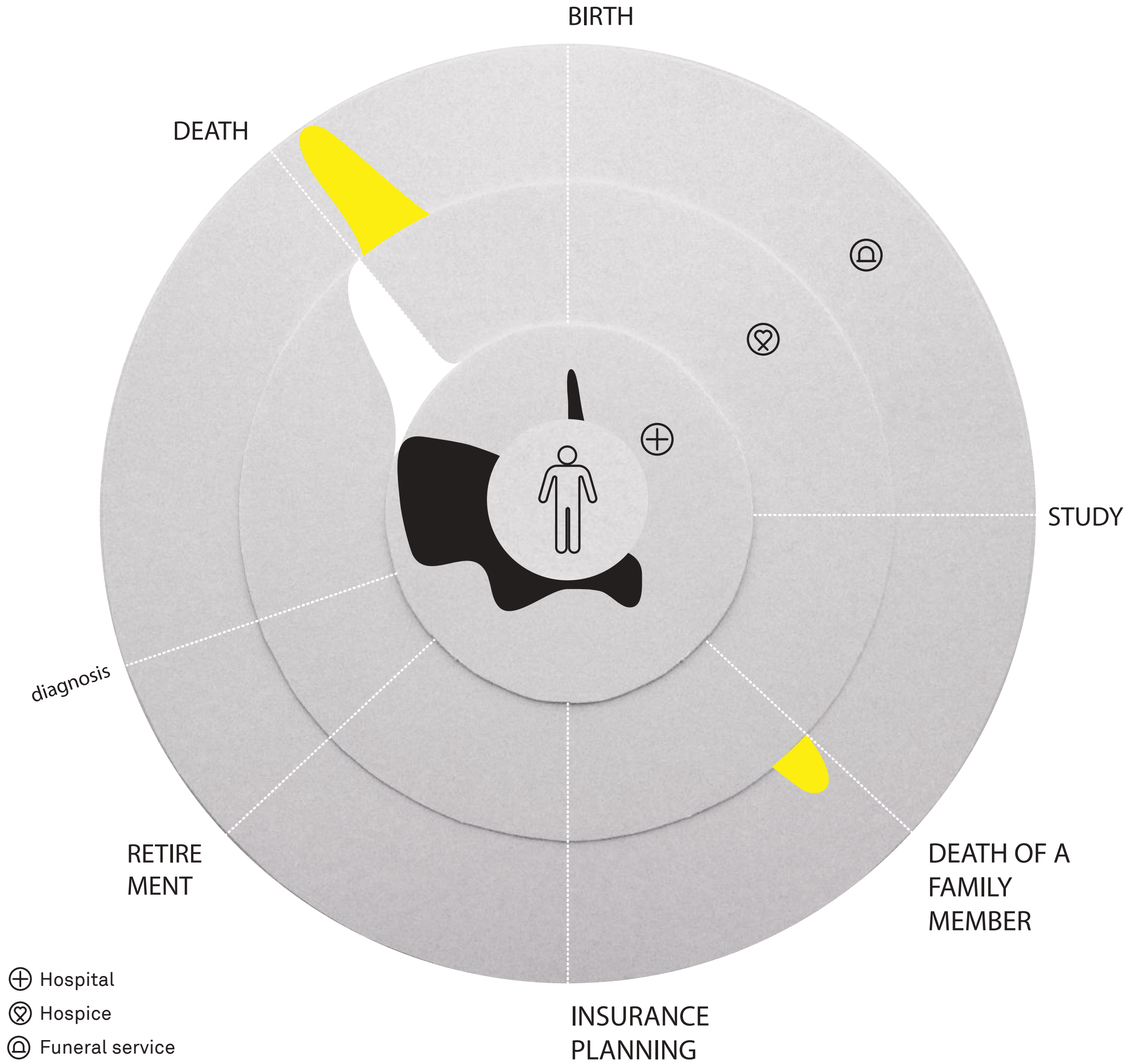
Celebrating life, beyond any given timeframe.

Funded in **systemic** and **sustainable** ways, engaging people to contribute as a part of their everyday life.

Triggering citizens to **face death** without fear, becoming **proactive** in the process.

Empowering patients and loved ones with a **sense of control**, allowing their **voices to be heard** along the end-of-life journey.

Connecting teams with a single palliative care **mindset**, to deliver **consistent** care services along the end-of-life journey.



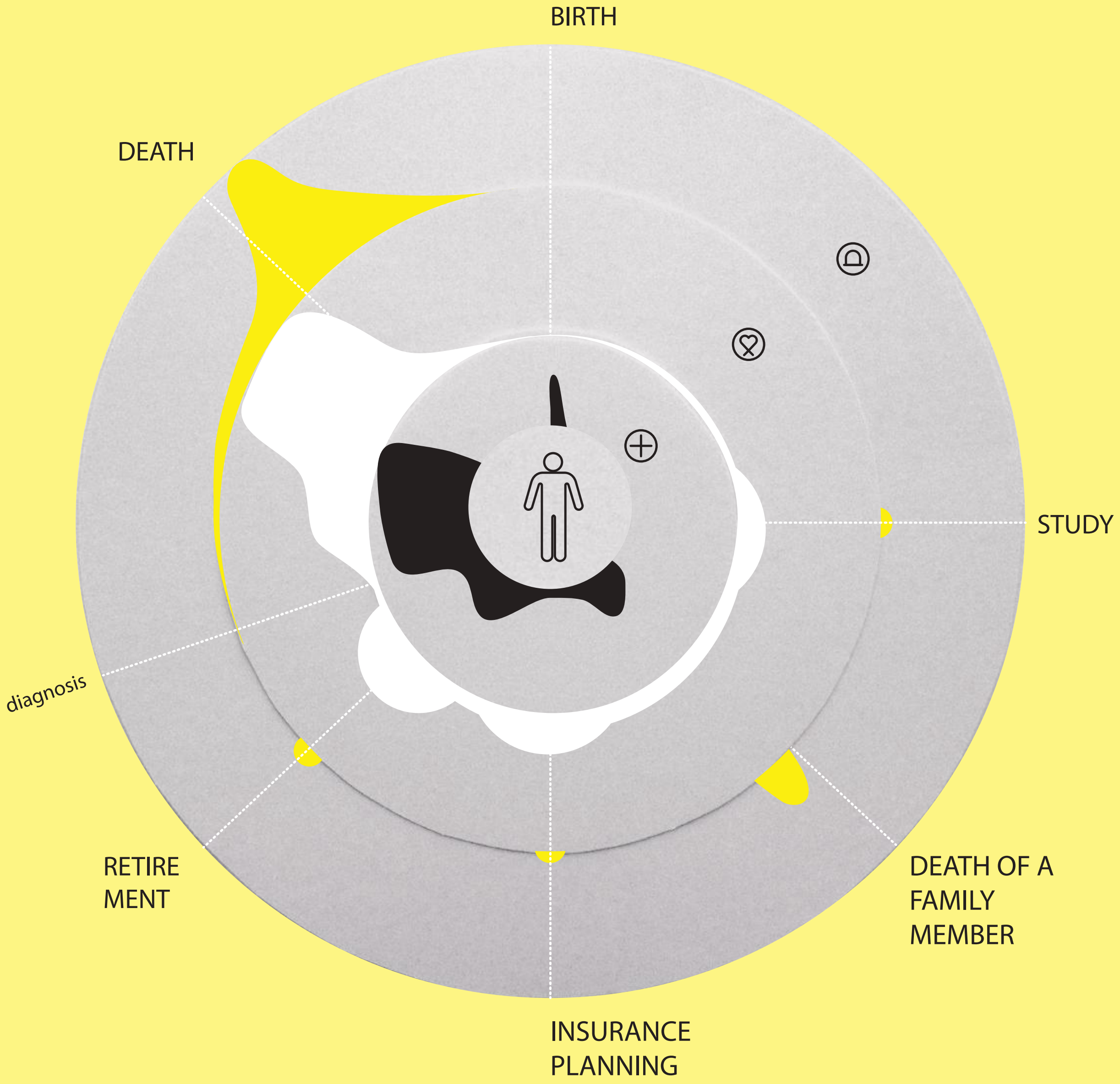
HOW IT IS TODAY ...

REFRAMING THE CARE JOURNEY, AS A LIFE JOURNEY

We propose using a life stages framework to reframe the hospice care experience. It spans over time from birth to death, and places the person at the centre. The concentric circles represent different settings and services; from healthcare to hospice and funeral care. The coloured segments represent significant touch points with each service along a typical life journey, with the peaks and troughs showing the intensity of the experience at that moment.

The story starts with a person being born, usually in a clinical hospital setting. There may be no major encounters with the healthcare system until around middle age, when there can be acute health events or chronic conditions that intensify with age (indicated by the black peaks). With the loss of a loved one, a brief funeral service touchpoint appears (yellow peak). Then at the point of a more significant and potentially life-threatening diagnosis, there can come a moment where a typical curative care approach no longer helps and palliative care is referred. The person is transferred to hospice services. Usually this transfer happens too late and therefore the stay in hospice care is short and intense (indicated by the white peak). After the death of a loved one, it is the family that have to recover from this intensity of loss and face many decisions and arrangements for funeral service under financial, time and emotional pressure (indicated by the yellow peak).

Today´s model is one of sudden handovers from one service provider to another with little advanced planning and a great deal of stress and anxiety. There is little or no formal overlap or cooperation between siloed organisations from acute care to hospice care to funeral care. The service experience of the patient and their loved ones tends to be discontinuous and inconsistent. Palliative care comes into the picture later than is desired or useful.



The story similarly starts with a person being born in a clinical hospital setting and facing few encounters with health care services. A key difference in this new model is that specific new touch points are introduced within the hospice service. For example through volunteering from an early age to engaging with hospice services after retirement and with diagnosis whenever this may occur. The topic of death and dying is broached and normalised early on in life. With middle age and retirement, health becomes more of a priority and looking ahead is natural. Palliative care is offered earlier, from the moment of a potentially life-threatening illness and to complement curative care. When curative care can no longer succeed, the person and their family are already supported by palliative care and the transition to hospice is less fragmented. With death less of a taboo and fearful subject, advanced plans can be made that fulfill a person´s wishes and support family decision-making in end-of-life and funeral care services.

HOW IT SHOULD BE

...

Tomorrow´s model is one of much smoother and more gradual transitions between service providers and settings along the life journey towards end-of-life and into bereavement. The footprint of the hospice service extends earlier but also longer throughout all life stages; hospice is no longer a place you only meet with at the end of your life or of that of a loved one. Hospice services play a relevant role at various life stages, they become familiar and trusted to you over time (indicated as a continuous white thread along your life) Hospice has an ongoing role to play inside each community, it lies on people´s path and now delivers a wider range of community services, facilities and activities. Funeral service touch points are scattered throughout life as friends and family members pass away. As death approaches, the service seamlessly enters to support loved ones in preparing for the loss and healing through bereavement.

KEY ISSUES & INSIGHTS

1. HOSPICE IS ISOLATED FROM SOCIETY

- Palliative care is compartmentalized into acute, long term, hospice or home care.
- Public advertisement of funeral homes and services are strictly controlled by government rules, and touting of funeral services is illegal in hospices and hospitals.

2. HOSPICE & FUNERAL SERVICES ARE NEGATIVELY PERCEIVED

- Sending a loved one to a hospice is seen as abandonment
- Leaving a body in a mortuary is seen as a sign of disrespect for the deceased.
- Hospice is still viewed as a ´death house´ that people want to avoid at all costs
- Hospice is seen as a depressing and strange place for professionals to work
- The actual hospice experience is usually better than people´s perceived experience.
- Faith-based hospices can seem less scary to believers of that faith.
- Funerals, like weddings, are seen as opportunities to show off your wealth, status and love for your loved one.
- Different cultures have different attitudes, perceptions and expectations and hospice care.

3. DEATH IS A TABOO SUBJECT

- Talking about death differently helps people behave differently at the end of life.
- If death is a societal conversation, people would be equipped to coach themselves through the journey.
- People don´t want to talk about death, they don´t have the courage.
- Hospice staff gradually reveal the truth to patients or families when they think they are ready.
- It is not death itself we fear but the moments before.
- Past practices dictate current mindsets. These include not leaving a dead relative alone, arranging a funeral in the shortest time possible and providing the best, are seen as signs of respect and love from relatives to the deceased.

4. LACK OF UNDERSTANDING ABOUT PALLIATIVE CARE

- Palliative care is relatively new in Singapore.
- There is a need for champions and role models in palliative care.
- The healthcare system is more medically-centric than socially-centric.
- There is widespread ignorance about palliative care across Singapore society at all levels.
- It is important to expose healthcare professionals to hospice work as part of their standard training.
- Demonstration is more powerful than verbal explanation to communicate a hospice care principles to staff in training.

5. SHORTAGE OF PALLIATIVE CARE PROFESSIONALS

- Trial periods are needed to effectively evaluate if staff can perform a palliative care role.
- There is a shortage of doctors and nurses with the right qualifications, experience and attitude for palliative care.
- Pioneering hospice organisations are partnering to create training courses that will disseminate their practical knowledge and experience to develop the professionals required.
- Training palliative care givers involves building a deep empathy and respect for patients and families.
- Palliative professionals need to have an attitude of self-assessment and a desire to continuously improve in order to evolve the field.
- Palliative care givers need to be able to transfer their knowledge and train peers in order to scale up experienced professionals.
- Social workers are in short supply so in hospices they have to focus on the most needy cases.
- Finding hospice staff with the right mix of clinical skills, personality traits, the right attitude and right heart is extremely tough.
- Strong communication skills, verbal and non-verbal, are an important criteria in recruiting staff.
- Despite progress to raise the status of nurses in Singapore, it is generally still difficult to attract and retain good people in the profession, even more so in hospice care.

6. INCONSISTENT SERVICE EXPERIENCE

- A patient-centric service will be most beneficial but the main limitations are money and coordination.
- There is a role for a case manager to accompany patients in their journey and avoid ´medical homelessness.
- Teams behave inconsistently in their care delivery, making coordination and communication harder.
- The lack of knowledge of what funeral services entail, including expected costs, creates a lot of anxiety among families of the deceased.
- Technology is used to overcome time and distance problems that arise when multidisciplinary teams in different locations need to work together to deliver care (video conferencing, email photos, SMS).
- Doctors try to be more informal and intimate in palliative care, spending time with the patient to inform, reassure and encourage.

7. DISCONTINUOUS INFORMATION FLOW

- Traditional healthcare hierarchies persist inside some hospices and can block effective information flow.
- Cultural and local language barriers exist between care givers, patients and loved ones preventing trust and intimacy.
- Care teams and families can help each other to keep well informed about the patients needs.
- The selection of a funeral home usually has to be done so quickly that it is mostly made by friends and family referrals.
- The national electronic patient record system is expected to make information flows smoother.
- Authenticity is essential in communication towards patients and loved ones.

8. MULTIDISCIPLINARY CARE TEAMS ARE CHALLENGED TO STAY FULLY INFORMED

- There is a need for professional collaboration across disciplines with a clear clinician leadership.
- Teams find practical, ad hoc and low tech ways to collaborate.
- Professional language barriers need to be overcome between disciplines involved in palliative care.
- To build a holistic and complete picture of a person, the team relies on each others ears, eyes and hands.
- Technology tools helps teams to stay in touch, exchange information, ask questions and take care decisions in spontaneous ways in in-patient, day care and home care services.
- A clear chain of communication between professionals and across levels of responsibility helps teams coordinate care; this chain can also include family.
- Visual tools help teams communicate care issues across disciplines and develop better ways to work together.

9. HOSPICES CAN ONLY PERFORM SUB-OPTIMALLY IN CONSTRAINED CONDITIONS

- Bureaucracy around end-of-life care planning and management needs to be made agile for hospice and palliative care teams to respond effectively to each patient situation.
- Even though they are not fully funded by the government for the services they provide, non-profit hospices feel obligated to take in more patients than is ideal due to their charitable mandate.
- In the face of resource shortages, hospices are struggling to scale up their services and even have to turn away people to maintain quality of care.
- There is a need for a new set of metrics to measure palliative care outcomes and performance accurately.
- Priorities vary from hospice to hospice depending on the care philosophy and service focus.
- Cloud computing will make processes more efficient but could also consolidate patient data to drive evidence-based care practices.
- Teams in hospices are generally less tech-savvy given the lower level of clinical care compared to hospitals - they need training in technology usage.
- Volunteer programs are trying to grow and become more structured and systematic in the way they recruit, train and assign members to support.

10. EXISTING FUNDING SOURCES CANNOT SERVE RISING DEMAND

- Finding viable and sustainable funding models for hospice care is a major challenge that is being met by hospices with ad hoc creative solutions.
- People, and middle class families in particular, cannot afford hospice care and are anxious about associated costs.
- Opportunities exist to streamline and balance cost with quality of care delivery in hospices.
- Many private insurances do not currently cover hospice or terminal care.
- Hospices face funding constraints, which mean that they have to prioritise care to specific groups: elderly and those with terminal chronic diseases.
- Hospices rely heavily on fundraising to fill the government subsidy gap, yet fundraising events are too predictable and are becoming less effective to meet a rising fundraising target.
- Encouraging volunteer programs can help fill a gap in resource shortages since they represent a free workforce for hospices, sometimes even being trained to attend to basic nursing tasks.

11. HOSPICE SPACES ARE NOT DESIGNED FOR PALLIATIVE CARE

- Most hospices in Singapore have been donated and not suited to deliver palliative care well.
- Although hospices do encourage families to participate in caring for their loved one, facilities are not always equipped for them to stay there comfortably.
- Staying mobile within the hospice fosters a sense of independence in patients, yet space is a premium.
- It is important to create a supportive environment and culture of care to foster the humanistic mindset in care givers; the right spirit of care.
- To deliver holistic care you need to have multiple disciplines working together: clinicians, nurses, social workers, therapists, pastoral care givers.
- Keeping a sense of normality in the schedule of daily routines (bathing, resting, mealtimes) can help patients settle into hospice life.
- Patients may need to be isolated and cared for with specific protocols when they pose an infection risk or become disturbing to others (foul smells, loud sounds).
- Teams explicitly monitor their risk and number of falls, working actively to prevent them by controlling the safe mobility of their patients or immobilising them.
- Loved ones express their love for the patient by bringing in food, though this is not always adequately supported in hospice space design.

12. PALLIATIVE CARE TEAMS NEED TO BE CARED FOR

- Working in palliative care is seen as a meaningful professional experience that brings immense personal satisfaction.
- Due to the close interaction staff have with patients and families in moments of pain and suffering, they have to define clear personal boundaries to stay strong.
- Although staff stress is recognised by hospice management, current solutions do not seem to be working and resignation or sabbaticals are the only ways out.
- Even though impartial, off-site therapy services are offered to staff, many do not use the service in case they look as if they are failures.
- Staff try to make their own strategies to cope with the stress of an emotionally draining job, such as leaning on each other in the team.
- Young foreign nurses can suffer homesickness that unsettles them personally, forces them to stick together and detaches them from staff and patients.
- Staff build morale and a sense of togetherness by sharing food and meals together.

13. LOVED ONES NEED ONGOING SUPPORT

- Filial piety means the younger generation feel obliged to take care of their parents.
- Busy lifestyles mean more families rely on domestic help to manage the household and care for kids and elderly.
- There is a need to balance respite care support with opportunities for active family engagement, to help manage a family´s stamina on the end of life journey.
- Emotional support is vital to offer in a timely and appropriate way, as loved ones experience a wide range of feelings from anger to relief and sadness.
- Every family is unique in the way they experience the various stages of the end of life journey and require tailored support.
- Having the time to accept an impending death helps families grieve for a shorter time.
- Advanced funeral planning of a patient can relieve the family of the stress of disagreements, discussion and decision-making around end-of-life arrangements.
- Hospice services only support families up to the moment of death and then hand over the deceased to the family, who then have to contend with and choose from a plethora of funeral service providers. They play a limited role after the deceased is handed over to a funeral director.
- Funeral Directors take the role of counsellor to console and offer emotional support to the family.
- Hospice care staff can build close relationships with patients and their families that allow them to provide continuity of care along the end-of-life journey, from hospice to wake.
- Relatives of deceased patients see volunteering as a way to give thanks and to give back to the service.

14. DECISION-MAKING IS HIGHLY STRESSFUL FOR PATIENTS/FAMILIES

- Patients get stressed when they feel they are a burden to their family; financially, emotionally and physically.
- Care givers can educate and empower the patient and family to prepare for and navigate the end-of-life journey.
- Talking about money issues with families and patients is a sensitive subject for hospice teams.
- Staff try to break the collusion between family members, and reveal the voice of the patient.
- Patients don't always feel empowered to communicate their needs and emotions; feeling grateful for care and not wanting to offend anyone.
- People trust doctors for advice more than nurses, especially if doctors manage their pain and show empathy and care.
- Loved ones can feel overwhelmed by the responsibility and sense of duty they have towards the patient, especially in the face of complex, urgent or critical decisions.
- Disintegrating family structures and mosaic lifestyles place additional pressure and challenges on any collective decision-making needed about end-of-life care and services.
- Families find ways to keep each other informed and updated about their loved one´s condition (facebook, email, phone) usually coordinated by the person who is the main care giver/visitor.

15. LACK OF PERSONALISATION

- Patients need support to have their voices heard.
- Hiding the truth about imminent death creates many misunderstandings and prevents personalization of end-of-life for the patient; it doesn't allow patients to say goodbye and manage their issues properly before they die.
- A basic care principle that applies to palliative care is to understand the patient behind the symptoms.
- Nursing care tends to be planned heavily around carrying out specific tasks, which can leave nurses with little time for high touch care.
- Therapy gives alternative ways for people to express their feelings at end-of-life using pets, art or music as the medium.
- Patients and their loved ones need privacy & sociability at different moments during their hospice stay.
- Each patient is unique and with particular needs and different levels of readiness to face death at different moments in time.

16. STILL LIVING WHILE DYING

- Boredom is a big problem as patients might wait passively in between planned activities or daily routines.
- Staying connected to family, friends and the world helps patients to fight isolation and depression.
- Giving people a sense of control over the manageable aspects of their death is important and empowering.
- Supporting personal hygiene routines and cleanliness is a practical and symbolic way to enhance patient dignity and comfort.
- Food is an important factor that can add quality to hospice life for everyone, but one that is often overlooked.
- Meal portions and presentation affect how patient´s feel about eating.
- Having a choice of food and a sense of freedom in eating can bring joy and pleasure to a patient.

TOMORROW´S HOSPICE IS MORE THAN A BUILDING

IT´S A SERVICE FOR LIFE.

CONCEPTS OVERVIEW

SEVEN WAYS TO REDESIGN THE HOSPICE CARE EXPERIENCE

Today´s hospice is not a welcome guest ´in our backyard´.

This design strategy aims to break down taboos about death and dying, and challenge the negative preconceptions people have about hospices. We propose to ´open up´ the hospice service to society in seven different ways. To transform it from the invisible and avoided service it is today, to one that is valued by the community and that people find important and relevant for their life.

Tomorrow´s hospice is a daily celebration of life.

The design vision is made up of seven different concepts that fit together to create an eco-system of new products, services, spaces, policies and campaigns. It is possible to zoom in and consider each concept in isolation, but the richness emerges when we think of them as a system of design changes that collectively can achieve a greater impact.

Care Central is the new name for the hospice and refers to a new type of care setting. It coordinates palliative care for a community, orchestrating hospice home care, day care, ambulatory and in-patient care. This facility sits within the next concept of **Open Hospice**, a service platform that ensures Care Central is integrated into the community via a range of outreach services and programming. **A Compass for the end-of-life** offers a ´red thread´of guidance and support via a set of communication tools that help people better navigate the end-of-life care journey. **Building Communication Bridges** bonds professional palliative care networks, creating an open and holistic communication platform that organises conversation threads around each patient. **Care Marketplace** is a concept that promotes volunteerism as a mechanism to open up the hospice service, and harness the enthusiasm of citizens as a vital ingredient to drive the Open Hospice vision. **Enjoying Life´s Little Pleasures** provides a host of ways to bring joyful moments into hospice life for patients, loved ones and staff throughout the daily program but also through special outings and events. Finally **Giving Patients a Voice** recognises that central to the hospice experience is the uniqueness of each patient and their story and situation; creating chances to personalise care can be the ultimate respect for human life at the end-of-life.
The illustration opposite shows how these concepts relate to each other; Open Hospice lies at the core of the design strategy, the qualities of transparency in service and community-integration being essential to the overall direction. Building Communication Bridges, Care Marketplace and Compass serve as important foundation to support the Open Hospice idea. While Giving Patient´s a Voice and Enjoying Life´s Little Pleasures are specific experiences that would take place for in-patients inside Care Central, reflecting the intimate nature of ´high touch´ care that is palliative care. This philosophy of care delivery inside the building drives the external physical form and layout, creating a new spatial model for hospice called Care Central.

The following pages explain each of the seven concepts in greater detail: starting with an overall description, illustrating with supporting research images and insights, visualising the concept and highlighting the most important design principles behind the ideas. The full set of 24 experience design principles can be found at the end of this section.

GIVING PATIENTS A VOICE

LIFE'S LITTLE PLEASURES

CARE CENTRAL

OPEN HOSPICE

CARE MARKETPLACE

BUILDING COMMUNICATION BRIDGES

A COMPASS FOR THE END-OF-LIFE

CARE CENTRAL


VER PARK HOSPICE
DOVER PARK HOSPICE
托福園
Every Moment Matters
DOVER PARK HOSPICE AMBULANCE PARKING ONLY
AMBULANCE

INSIGHTS

CARE CENTRAL

HOSPICE SPACES ARE NOT DESIGNED FOR PALLIATIVE CARE

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- Although hospices do encourage families to participate in caring for their loved one, facilities are not always equipped for them to stay there comfortably.
- Staying mobile within the hospice fosters a sense of independence in patients, yet space is typically at a premium.
- It is important to also create a supportive environment and culture of care to foster the humanistic mindset in care givers; the right spirit of care.
- To deliver holistic care you need to have multiple disciplines working together: clinicians, nurses, social workers, therapists, pastoral care givers.
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THERE IS A SHORTAGE OF TRAINED PALLIATIVE CARE PROFESSIONALS

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- Despite progress to raise the status of nurses in Singapore, it is generally still difficult to attract and retain good people in the profession, even more so in hospice care.

“HOW DO YOU TRAIN PEOPLE TO BE GOOD AT THIS JOB? YOU HAVE TO CREATE THE ENVIRONMENT AS WELL.”

Dr Tan Yew Seng
Medical Director,
Assisi Hospice

A bedside cabinet is provided for every in-patient to keep their personal belongings.

A 7a.m. shift change meeting where the night shift nursing team transfer updated information about patients to the day shift nursing team.

A specialised hospice bed in an empty in-patient room that is being prepared for a new admission.

“MAYBE I´M A BIT SELFISH TO MY FAMILY, BUT I HAVE BEEN ILL FOR SO LONG THAT I FEEL IF I NEED TO GO, IT´S OKAY...”

Hospice in-patient

CARE CENTRAL

CARE CENTRAL IS A MODEL FOR AN END-OF-LIFE CARE SETTING THAT IS DESIGNED AROUND THREE CORE AXES. THE MAIN AXES RUN FROM PUBLIC-TO-PRIVATE AND SOCIAL-TO-SOLITARY THAT WORK TO FLEXIBLY SUPPORT THE CHANGING NEEDS OF PATIENTS, LOVED ONES AND CARE TEAMS WHO LIVE IN, WORK IN AND VISIT THE HOSPICE. THE THIRD AXIS RELATES TO THE LEVEL OF CLINICAL CARE, WHICH IS PRESENT AT ALL LEVELS OF THE BUILDING, BUT CAN VARY IN INTENSITY ACROSS THE FLOOR. IN THIS WAY THE OVERALL SPACE OFFERS A GRADIENT OF EXPERIENCES, OPEN TO PUBLIC INTERACTION AND DIALOGUE WITH LOCAL AND PROFESSIONAL COMMUNITIES, BUT ALSO CLOSED TO PROVIDE PATIENTS AND LOVED ONES WITH A STRONG SENSE OF SECURITY AND REASSURANCE AT THE VERY END OF LIFE, WHILST SUPPORTING CARE TEAMS IN DIFFERENT LEVELS OF PATIENT MONITORING BASED UPON CLINICAL NEED.

The integrated medical core supports a variety of palliative care delivery activities and stores medical supplies and equipment; the volume of this element can be varied according to the level of clinical focus appropriate for each facility and service. The upper floors where patients are more vulnerable or nearer the end-of-life is where clinical care is most intense and teams can monitor and intervene with patients more closely. There are semi-private spaces here for professionals to huddle spontaneously and informally to discuss case issues and take decisions quickly as a patient´s situation changes.

The medical core is designed primarily to support care professionals, and therefore stands in contrast to the other lifestyle-related areas of the building that are open to patients, families, loved ones, volunteers and the public. The ground floor is open for public access. The first floor is a more social and mixed space where patients and families can tap on support services to discuss their challenges with professionals and other members of the community who face similar issues. The second floor is the in-patient area. The rooftop garden is used for rehabilitation and relaxation. The ground floor's Saying Goodbye Garden offers a more dignified exit from the Care Central for family members to accompany the deceased.

The quality of transparency allows care givers to be seen as individuals thus ´normalising´ their interactions with patients and loved ones. It is a conscious choice not to segregate the sick from the well, to remove the stigma associated with disease and dying. This is necessary also amongst the professional clinical community, where there is a need to train and inform professionals about palliative care and ensure medical students and trainees are exposed to situations of death and dying in order to develop the skills and empathy to deal with them effectively, sensitively and safely. The Care Central Lab is a physical space and a meeting point for professionals from different locations to collaborate and transfer knowledge, experiences and skills. It provides safe support to care for care teams, as they care for patients and families. In this way The Lab is a test bed for piloting innovations in palliative care, helping to further the profession as a whole.

Integrating Care Central within the local community creates a chance to maximise the overall footprint of the building and make best use of land, while optimising the performance of Care Central as a set of unique modules.

Volunteerism is at the core of the vision for tomorrow´s hospice. A free, dedicated and skilled-up workforce can support a wide variety of care services for the community. Placing the volunteer space front and centre of Care Central deliberately positions volunteering on the community´s doorstep and facilitates a ´marketplace´ for recruitment and communication of available and needed services.

Bringing life into Care Central through thoughtful programming; a Library contains books for reflection and entertainment, the Auditorium is designed to host programmes that are of interest to the local community, the Café serves affordable and healthy food for Care Central staff, families, patients and the community. These activities and services will draw the community in, but also make sure that families are comfortably catered for while staying close to their loved ones.

Related to this, nature is used as a natural way of attracting people into Care Central; the public come in for lunches in the garden, children and families to play, staff for respite and patients or loved ones for spiritual

CARE CENTRAL

1 SMOOTH ADMISSION TO IN-PATIENT CARE ALLOWS PATIENTS TO CHECK-IN ONLINE WITH THE HELP OF THE CARE NAVIGATOR

Patients from the local community will experience a smooth transition from home care / day care services to the in-patient care service. With the help of their Care Navigator patients can set-up their preferences and check-in online prior to arriving at Care Central. They will be greeted at the café entrance.

2 VOLUNTEER CAFÉ PROMOTES VOLUNTEERISM THROUGH TRANSPARENCY OF INFORMATION AND ACCESS

The ground floor of Care Central is an open space that allows the public to enter the premises and freely use its services: garden, auditorium, café, restaurant. The notion of a Volunteer Care Marketplace, where services are both offered and provided by the community, promotes volunteerism. The physical location for this is at the Care Central Café, where visitors can easily find out more about the ways they can support the care service.

3 FLEXIBLE COMMUNAL AREA FOR CO-WORKING, TRAINING AND SOCIAL OR PRIVATE ACTIVITIES

The first level of Care Central accommodates mixed-used functionality that flexibly adapts to various activities: co-work spaces, spaces for group activities, and spaces for spiritual contemplation or intimacy. During part of the day many spaces are used by the home, day and in-patient hospice services, for the rest of the time it is open to the public.

4 CARE TEAM ACTIVITIES ARE INTEGRATED INTO THE PATIENT AREAS

The in-patient level is solely dedicated to patients and their loved ones. Nurses and doctors are integrated into the patient community, being located in the public areas just outside of patient houses. This allows them to spontaneously confer, monitor discreetly and intervene responsively. These public spaces offer a sense of security and yet also a stimulating environment for patients and loved ones.

5 MOBILE MEDICATION DISPENSING TO PATIENTS

Nurses can administer care at the patient bedside using a small mobile workstation trolley they can load with medications, case files, water/snacks.

6 ADAPTABLE MODES OF ACCOMMODATION TO SUIT A PATIENT´S CONDITION AND STATE-OF-MIND

On the in-patient level patients are accommodated in houses that can be configured for various modes, including: individual, intimate with close loved one, family mode or social mode. These houses can flexibly adapt to the real needs and requirements of the patient and loved one, while offering a true new home. Night shift staff also have a house in which they can rest if necessary.

7 ROOF GARDEN FOR RECREATION AND REHABILITATION ACTIVITIES

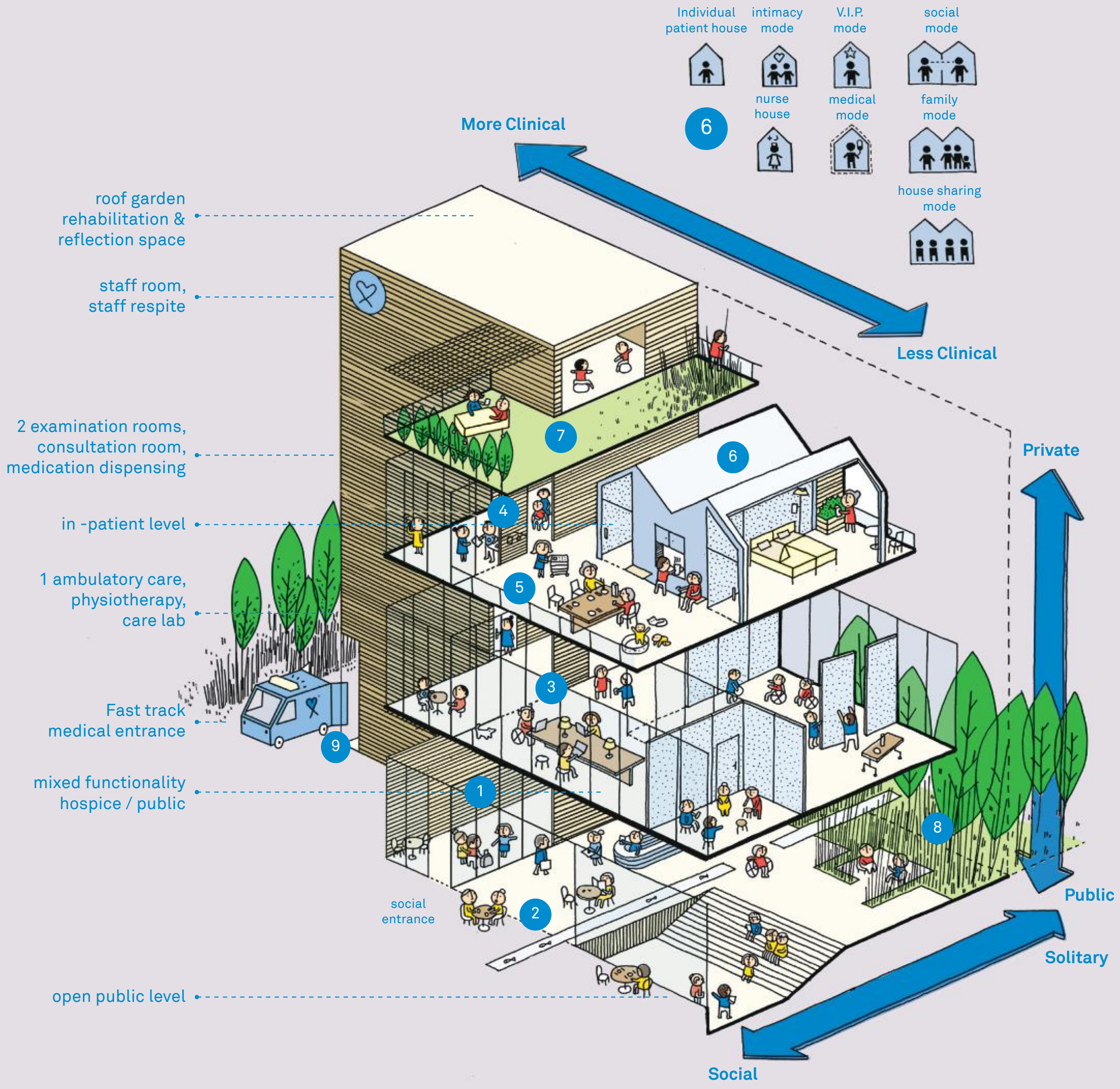
The roof garden is closed off to the public, it is mainly used by the day care / in-patients. The roof garden is a multi-functional space offering recreational activities, spaces for reflection and hobbies, as well as an integrated rehabilitation program using outdoor activities for physical, social and cognitive rehabilitation.

8 CHILDREN´S WATER PLAYGROUND BRINGS LAUGHTER AND ENERGY INTO THE GARDEN

Recreational features and activities can draw local citizens into Care Central. Young families can enjoy the park with their children, elderly and hospice patients can benefit from the vitality that children bring to any space they inhabit.

9 SAYING GOODBYE GARDEN

The Saying Goodbye garden is located at the rear of Care Central on the ground level, separated from the main back garden. This is the last touch point for loved ones to escort the deceased, where they can say their farewell in a private, dignified and considered space.


Individual patient house
intimacy mode
V.I.P. mode
social mode
6
nurse house
medical mode
family mode
house sharing mode
More Clinical
Less Clinical
Private
Public
Solitary
Social
roof garden rehabilitation & reflection space
staff room, staff respite
2 examination rooms, consultation room, medication dispensing
in -patient level
1 ambulatory care, physiotherapy, care lab
Fast track medical entrance
mixed functionality hospice / public
social entrance
open public level
1
2
3
4
5
6
7
8
9


1
ADMISSION STEPS:


2
VOLUNTEERS
MENU


3
LAB


8


9


7


5


4

SMOOTH ADMISSION TO IN-PATIENT CARE ALLOWS PATIENTS TO CHECK-IN ONLINE WITH THE HELP OF THE CARE NAVIGATOR

VOLUNTEER CAFÉ PROMOTES VOLUNTEERISM THROUGH TRANSPARENCY OF INFORMATION AND ACCESS

CHILDREN´S WATER PLAYGROUND BRINGS LAUGHTER AND ENERGY INTO THE GARDEN

MAKING VOLUNTEERING VISIBLE AND ATTRACTIVE

raise the profile of volunteers and encourage civic participation and the notion of ´giving back´ to the community to vitalise your hospice services.

FLEXIBLE COMMUNAL AREA FOR CO-WORKING, TRAINING AND SOCIAL OR PRIVATE ACTIVITIES

CARE TEAM ACTIVITIES ARE INTEGRATED INTO THE PATIENT AREAS

MOBILE MEDICATION DISPENSING TO PATIENTS

ROOF GARDEN FOR RECREATION AND REHABILITATION ACTIVITIES

SAYING GOODBYE GARDEN

INTEGRATE NATURE IN CARE

go beyond a merely ´cosmetic´ use of nature to distract and soothe the senses and find surprising and effective ways to incorporate natural elements and settings into care plans and the overall hospice experience.

GUIDE PEOPLE THROUGHOUT THEIR CARE JOURNEY

think about ways you can ´hold the hands´ of patients, loved ones and trainee care givers as they move through your service.

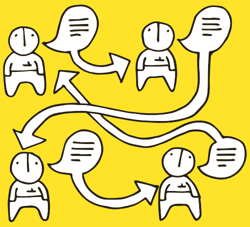
OPEN SERVICES TO WIDER PUBLIC

removing stigmas, fears and barriers to addressing end-of-life issues requires reaching everyday people in their everyday lives with interesting, relevant and accessible services.

DON'T SEPARATE THE SICK FROM THE HEALTHY

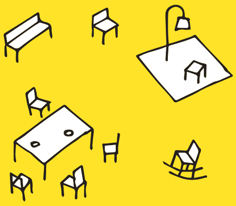
removing stigma around end-of-life and hospice services means treating all people equally, in the face of illness.

DIRECT COMMUNICATION BETWEEN STAKEHOLDERS



hospice services require many people to work together to deliver optimum care, so work on keeping people well informed and involved to ease communication and clarify both decision-making as well as create room for reflection.

SPACES ADAPT TO USER



end-of-life is unpredictable and people´s condition, feelings and preferences can change spontaneously and dynamically during their hospice stay, spaces must therefore adapt to meet these ever-changing needs.

DIGNIFY EMOTIONAL MOMENTS IN THE JOURNEY

recognise that it is normal for people to experience emotional breakdowns and feel vulnerable, but make sure they can feel safe and secure at these times.

CREATE A SAFE ENVIRONMENT TO EXPRESS FEELINGS

create a sense that any feeling is an acceptable feeling to be had inside a hospice, for patients, loved ones and staff, and that there is a considered ´place´ for this sentiment both literally and emotionally.

MAKING IT REAL...

CARE CENTRAL

Care Central is a conceptual model whose key axes can be applied flexibly to different architectural plans, whilst maintaining the same gradient of experiences. They can be applied to buildings that are structured horizontally, vertically or in combination of the two.

The Medical core can be varied in volume to support different levels of clinical care and therefore make the concept more broadly applicable to intermediate and long term care settings; some hospice services are within nursing homes and deliver lower levels of clinical care, compared to others that are in palliative care departments within acute settings handling more complex clinical cases.

Tuning the programming of Care Central to the local community can increase its potential impact; consider ways to engage the local community in space planning and program design by facilitating workshops with key stakeholders. Bringing the voice of the community into your process can build ownership of the results and foster a sense of pride in delivering the new hospice service.

POTENTIAL PILOT PROJECTS

GOODBYE GARDEN

- In most hospices the area where the deceased is taken by the funeral company tends to be located at the back of the facility, where trash is left for collection and service deliveries take place. It would be relatively easy to improve this experience, since today it is neglected, and it could make a huge difference to families at a major pain point in their bereavement journey.

LET THE COMMUNITY IN:

- Consider ways to incorporate community spaces (e.g. garden, auditorium or café) into your existing or new building plans. Think about how you can make your building an attractive destination that people want to visit. Analyse and understand better the profile of your local community. Find out what services might be lacking or considered valuable. If you cannot influence the building structure you can also experiment with the services you offer in your existing space; try for example a weekly kopitiam service open also to the local community. Or play with interior elements (plants, fountains and shaded features) that draw people in for respite.

CARE LAB

- Formalise existing palliative care training activities and support development of the profession by creating a dedicated space to share experiences, skills and knowledge. This need not be a dedicated room to start with, but could begin as programming event to test interest and tune content. With a dedicated space, however, you can start to test ways to interact as a palliative professional community: role playing to train staff through demonstration and scenarios, Open Days to promote and attract new talent, informal lunches that can act as staff support sessions.

LIVING QUALITIES

- Prototype design ideas to test and find the most suitable non-clinical interior qualities for palliative care. This project would aim to define a ´spatial signature´ that reflects life, and the holistic and people-centred nature of palliative care. Consideration can be given to the design of interior elements: layout, architecture and furniture and furnishings as well as signage and communication tools.


Care Central Cafe
Volunteer here
Earn Care Credits!
By volunteering at the Care Hub, you can earn care credits, that can be used at various programs at the Care Hub...
This month our volunteers earned
2034 care credits
LAST MEAL MENU
CARE CENTRAL CAFE

THE OPEN HOSPICE

INSIGHTS

OPEN HOSPICE

HOSPICE IS ISOLATED FROM SOCIETY

- Palliative care is compartmentalized into acute, long term, hospice or home care.
- Public advertisement of funeral homes and services are strictly controlled by government rules, and touting of funeral services is illegal in hospices and hospitals.

HOSPICES & FUNERAL SERVICES ARE NEGATIVELY PERCEIVED IN SOCIETY

- Sending a loved one to a hospice is seen as abandonment
- Leaving a body in a mortuary is seen as a sign of disrespect for the deceased.
- Hospice is still viewed as a ´death house´ that people want to avoid at all costs
- Hospice is seen as a depressing and strange place for professionals to work
- The actual hospice experience is usually better than people´s perceived experience.
- Faith-based hospices can seem less scary to believers of that faith.
- Funerals, like weddings, are seen as opportunities to show off your wealth, status and love for your loved one.
- Different cultures have different attitudes, perceptions and expectations and hospice care.

DEATH IS A TABOO SUBJECT

- Talking about death differently helps people behave differently at the end of life.
- If death is a societal conversation, people would be equipped to coach themselves through the journey.
- People don´t want to talk about death, they don´t have the courage.
- Hospice staff gradually reveal the truth to patients or families when they think they are ready.
- It is not death itself we fear but the moments before.
- Past practices dictate current mindsets. These include not leaving a dead relative alone, arranging a funeral in the shortest time possible and providing the best, are seen as signs of respect and love from relatives to the deceased.

LOVED ONES NEED ONGOING SUPPORT

- Filial piety means the younger generation feel obliged to take care of their parents.
- Busy lifestyles mean more families rely on domestic help to manage the household and care for kids and elderly.
- There is a need to balance respite care support with opportunities for active family engagement, to help manage a family´s stamina on the end of life journey.
- Emotional support is vital to offer in a timely and appropriate way, as loved ones experience a wide range of feelings from anger to relief and sadness.
- Every family is unique in the way they experience the various stages of the end of life journey and require tailored support.
- Having the time to accept an impending death helps families grieve for a shorter time.
- Advanced funeral planning of a patient can relieve the family of the stress of disagreements, discussion and decision-making around end-of-life arrangements.
- Hospice services only support families up to the moment of death and then hand over the deceased to the family, who then have to contend with and choose from a plethora of funeral service providers. They play a limited role after the deceased is handed over to a funeral director.
- Funeral Directors take the role of counsellor to console and offer emotional support to the family.
- Hospice care staff can build close relationships with patients and their families that allow them to provide continuity of care along the end-of-life journey, from hospice to wake.
- Relatives of deceased patients see volunteering as a way to give thanks and to give back to the service.

EXISTING FUNDING SOURCES CANNOT SERVE RISING DEMAND

- Finding viable and sustainable funding models for hospice care is a major challenge that is being met by hospices with ad hoc creative solutions.
- People, and middle class families in particular, cannot afford hospice care and are anxious about associated costs.
- Opportunities exist to streamline and balance cost with quality of care delivery in hospices.
- Many private insurances do not currently cover hospice or terminal care.
- Hospices face funding constraints, which mean that they have to prioritise care to specific groups: elderly and those with terminal chronic diseases.
- Hospices rely heavily on fundraising to fill the government subsidy gap, yet fundraising events are too predictable and are becoming less effective to meet a rising fundraising target.
- Encouraging volunteer programs can help fill a gap in resource shortages since they represent a free workforce for hospices, sometimes even being trained to attend to basic nursing tasks. gap in resource shortages since they represent a free workforce for hospices, sometimes even being trained to attend to basic nursing tasks.

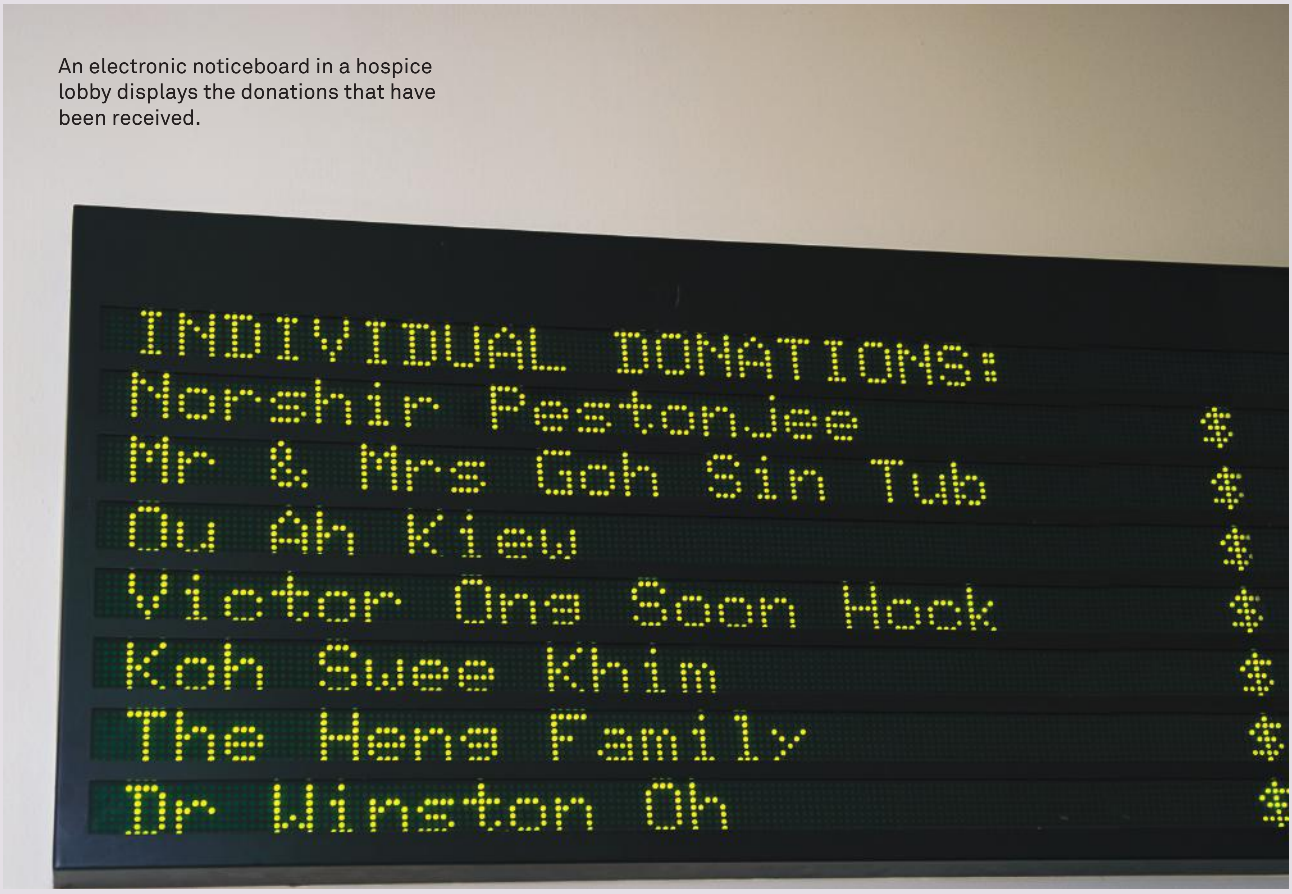
“A HOSPICE SHOULD BE EMBEDDED IN THE HEALTHCARE SYSTEM... YOU DON´T CONTAIN A SERVICE BY WALLS.”

Sister Geraldine Tan,
Administrator St Joseph´s
Nursing Home & Hospice

The final journey starting from the Mount Vernon Sanctuary, Singapore.

A home care nurse uses an orange to demonstrate to a family member how to inject morphine and relieve a patient's pain.

One of the streets in Singapore where funeral homes are clustered.



An electronic noticeboard in a hospice lobby displays the donations that have been received.

¨IN THE BEGINNING, I REMEMBER I WAS SCARED TO GO INTO THE WARDS. BUT THEN LITTLE BY LITTLE I STARTED TO ENJOY BEING HERE.¨

Hospice volunteer

THE OPEN HOSPICE

OPEN HOSPICE IS A COMMUNITY-BASED SERVICE THAT IS LOCATED ALONGSIDE THE INGREDIENTS OF A TYPICAL SINGAPORE NEIGHBOURHOOD: MARKET, HOSPITAL, SCHOOL, KINDERGARTEN, PRAYER HOUSE AND RESIDENTIAL BLOCKS (E.G. HOUSING DEVELOPMENT BOARD). OPEN HOSPICE CREATES TRANSPARENCY BETWEEN THE HOSPICE SERVICE AND THE SURROUNDING NEIGHBOURHOOD BY EXTENDING HOSPICE CARE AND PROGRAMMING INTO THE COMMUNITY. AS WELL AS INVITING THE COMMUNITY TO ENGAGE WITH HOSPICE SERVICES. IN THIS WAY OPEN HOSPICE CAN HELP TO SHIFT PUBLIC PERCEPTION OF HOSPICES, RAISE AWARENESS OF END-OF-LIFE ISSUES, WHILST GENERATING NEW REVENUE STREAMS AND DELIVERING CARE AT A GRASSROOTS LEVEL. TOMORROW´S HOSPICE BECOMES A PART OF THE SOCIAL FABRIC.

In this integrated care model the hospice service becomes a coordination point for a range of palliative care services that are distributed, both physically and virtually, around the neighbourhood; home care givers can attend training classes and support groups at Care Central, as well as receive a variety of mobile services such as food delivery and on-site nursing support within their HDB.

Additionally, when the hospice service has responsibility as care coordinator, patients can move more fluidly between a spectrum of palliative care services: from home care to day care and ambulatory care with in-patient care as and when required.

In order to safeguard consistency across services and settings, Care Central offers its own transportation service to support for instance: home care food delivery, home care clinical visits, hospice transfers from home or to hospital, funeral service transfer for the family with the deceased. In this way the patient and their loved ones can be supported continuously along their care journey.

Local activities are designed to support Care Central; a class of school kids ´adopt´ an in-patient from Care Central to get to know each other. The wet market is a natural meeting point for the community and Care Central would have a stall here; products made by patients and volunteers in Care Central can be sold and volunteers manning the stall can keep in touch with families and elderly in the neighbourhood. Local groups can lease spaces in Care Central for running workshops, events or screenings.

A benefit of the increased transparency of the hospice service lies in attracting more volunteers from the local community. As more people become aware of and interested in the activities within Care Central, the general level of awareness around end-of-life issues can grow and find a place in the context of people’s everyday life. In this way, starting a conversation about death and dying becomes less threatening, more engaging and intuitive.

THE OPEN HOSPICE

1

SELLING THANK YOU COOKIES AS PART OF AN AWARENESS CAMPAIGN

Handmade gifts and products from Care Central, produced by patients, families or volunteers, can be sold at local outlets such as the market, to raise funds and build awareness about Care Central and its programs. Breaking down taboos in a gentle way, through gift-giving. Expressing the voice of patients and families out into the community.

2

SCHOOLCHILDREN ADOPT MR. TAN FROM CARE CENTRAL

Local schoolchildren carry out a project to document the life story of an in-patient at Care Central. Spending time with him, getting to know his life story, capturing his words of wisdom, documenting it in a book with words and visuals. Ultimately helping to create a memento for him and his family. As they work on this project they begin to confront end-of-life issues and learn to ´give back´from a younger age.

3

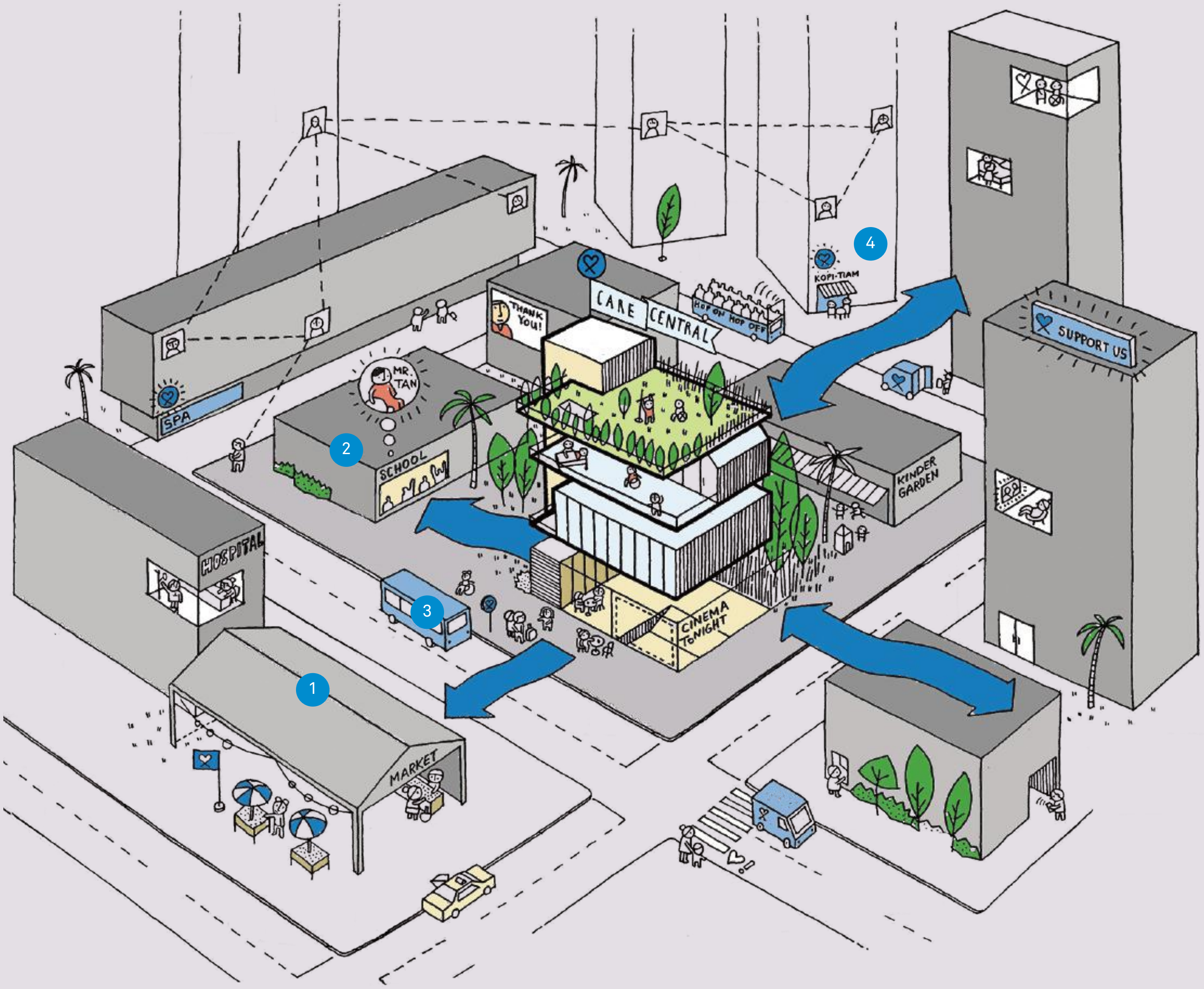
CARE BUS SERVES THE LOCAL COMMUNITY WITH ROUTES THAT PASS THROUGH CARE CENTRAL

Local transportation is provided by Care Central to assist elderly in the community to stay active, mobile and independent. It also provides practical transfer to and from Care Central for home hospice patients who might need the ambulatory service, or for day care patients to come to Care Central for their sessions.

4

CARE CENTRAL FOOD DELIVERY SERVICE THAT KEEPS AN EYE ON LOCAL ELDERLY AND HOME HOSPICE PATIENTS

Home food delivery service that can cater to the specific dietary and nutritional needs of elderly and home hospice patients being cared for at home. Whilst delivering food, care givers can check on both the patient as well as their loved ones to see how they are coping and if they need any additional support, information or

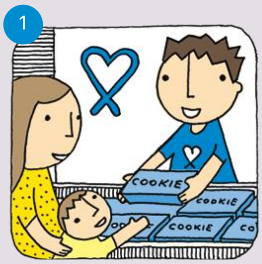

SPA
MR. TAN
SCHOOL
THANK YOU!
CARE CENTRAL
HOP ON HOP OFF
KOPI-TIAM
SUPPORT US
KINDER GARDEN
HOSPITAL
CINEMA TONIGHT
MARKET
1
2
3
4


COOKIE
COOKIE
COOKIE
1


2


CARE HUB
3


FOOD
4



1

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2

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4

SCHOOLCHILDREN ADOPT MR. TAN FROM CARE CENTRAL

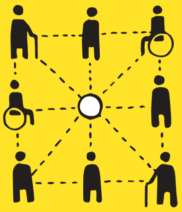
DON'T SEPARATE THE SICK FROM THE HEALTHY

removing stigma around end-of-life and hospice services means treating all people equally, in the face of illness.

3

CARE BUS SERVES THE LOCAL COMMUNITY WITH ROUTES THAT PASS THROUGH CARE CENTRAL

PROVIDE ACCESSIBLE CARE



design services to feel as if they lie on people´s path, on their doorstep, within their reach - both physically as well as virtually.

CREATE A COHERENT CARE BRAND

define a visually iconic and consistent service identity that expresses itself at every touchpoint so that people become familiar with and trust the service and can better navigate along the end-of-life journey.

RECOGNISE THE PERSON BEHIND THE PATIENT

palliative care is holistic so patients must be taken care of beyond their disease, but with attention given also to the context of their lifestyle, their unique family set up, personal capabilities and beliefs.

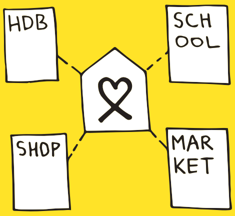
INTRODUCE EARLIER TOUCHPOINTS TO CARE

consider that engagement with end-of-life and hospice services can begin from a young age and last throughout a lifetime to build a unique and personal service for any citizen.

OPEN SERVICES TO WIDER PUBLIC

removing stigmas, fears and barriers to addressing end-of-life issues requires reaching everyday people in their everyday lives with interesting, relevant and accessible services.

BUILD NEIGHBOURHOOD CARE COMMUNITIES



discover ways to harness the power of crowds, leverage the natural behaviour and dynamics of communities to foster a more sustainable model of care enhancing the hospice service itself.

MAKING IT REAL…

THE OPEN HOSPICE

During the feedback sessions this concept was well received by palliative professionals and experts, seeing it as a positive and inspiring vision to work towards. This idea requires strategic and operational partnerships to be formed between different healthcare providers and community organisations. There are challenges to overcome as currently different providers are constrained, governed and regulated by different authorities. However, building upon existing infrastructure and services, for example that of local Residents Committees and Community Centres, can make the first steps towards implementation of Open Hospice feasible.

Recent developments in the Singapore healthcare landscape hold similarities to the overall concept direction of Open Hospice. The Woodlands development project that is nicknamed ´vertical kampong´ involves the collaboration of multiple agencies including a public healthcare provider and the government’s housing development board (HDB). The project is piloting a new model of healthcare delivery that is community-integrated. Woodlands will offer settings in which people can live, work and age-in-place: studio apartments, a hawker centre, a medical centre, shops, childcare facilities and a seniors’ activity centre. Novena Health City is yet another initiative underway: its vision is that of a networked healthcare delivery model that connects services to the community through Care Hubs - hospice care is included.

POTENTIAL PILOT PROJECTS

NOURISHMENT PACKS

- Understand from home care givers what might be valuable to include in such packs and how to tailor communication to support the specific needs of busy families looking after loved ones at home - information about support services and training courses, self-care tips and advice, symptom troubleshooting, provision of meals for the elderly or infirm, surprise treats for the whole family to enjoy. Home delivery creates a chance for healthcare providers to deliver ´soft care´ and simply check on how the family is coping.

SHARED PROGRAMMING

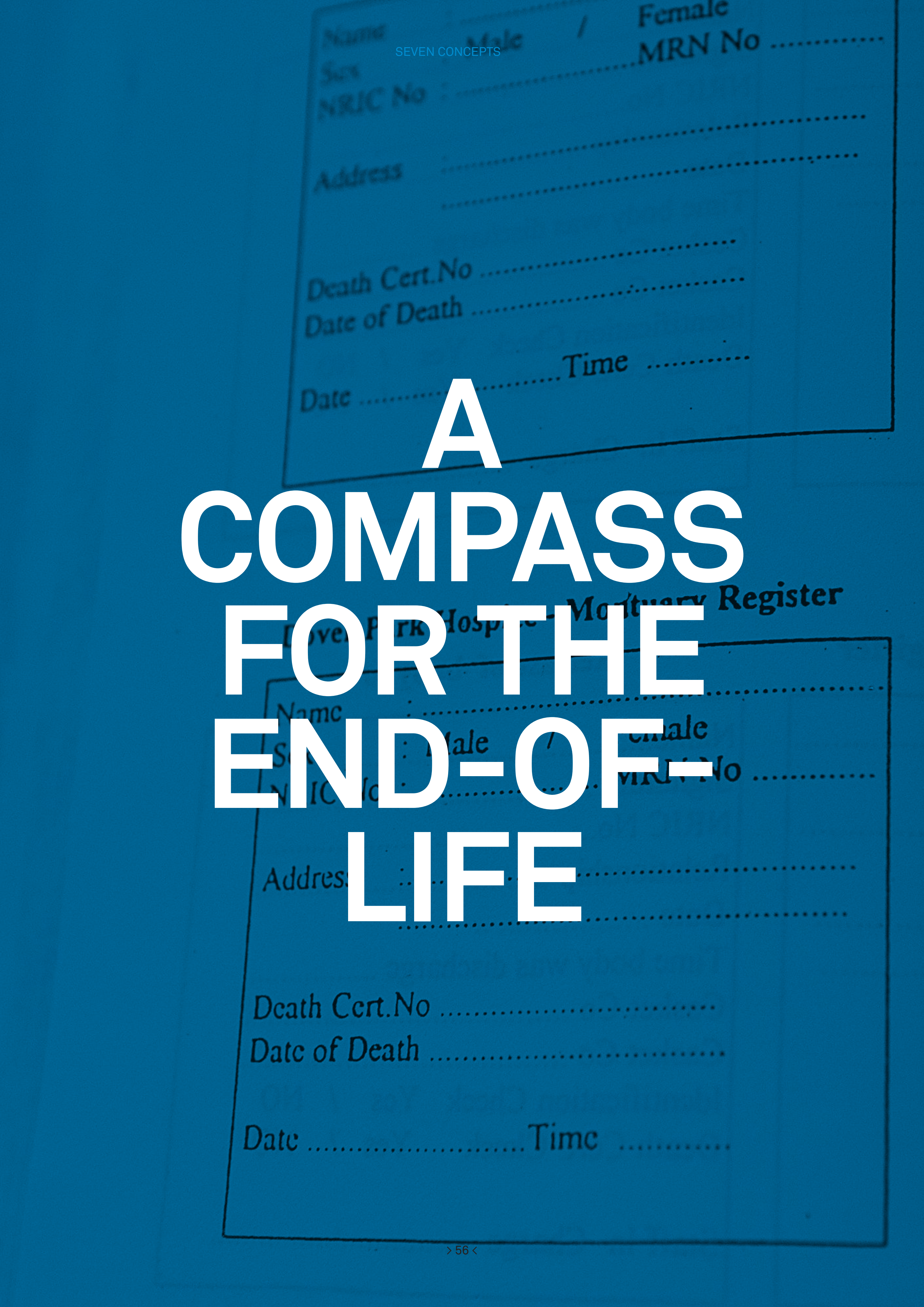
- Investigate ways to collaborate with kindergartens, schools, colleges and universities to define projects that can enrich in-patient life and build awareness in hospice care: legacy work and life story projects, hosting of activities and events to bring youth and energy into the service.

CARE SOUVENIRS

- Create a range of products that can be made in Care Central then shared or sold in and around the community to raise the profile of the hospice service, its people, their voices and experiences e.g. Thank You Cookies.


NOURISHMENT
PACK
Enjoy your meal
Mr. Jeffrey Goh!
Today's pack includes
Weekly Care Plan
Care Central Agenda
Care Marketplace off
one Special Meal
one Care giver Meal
6/13/15
MENU 2
Mrs. Tan, Blk 123 #0
lands St 81, Singapor

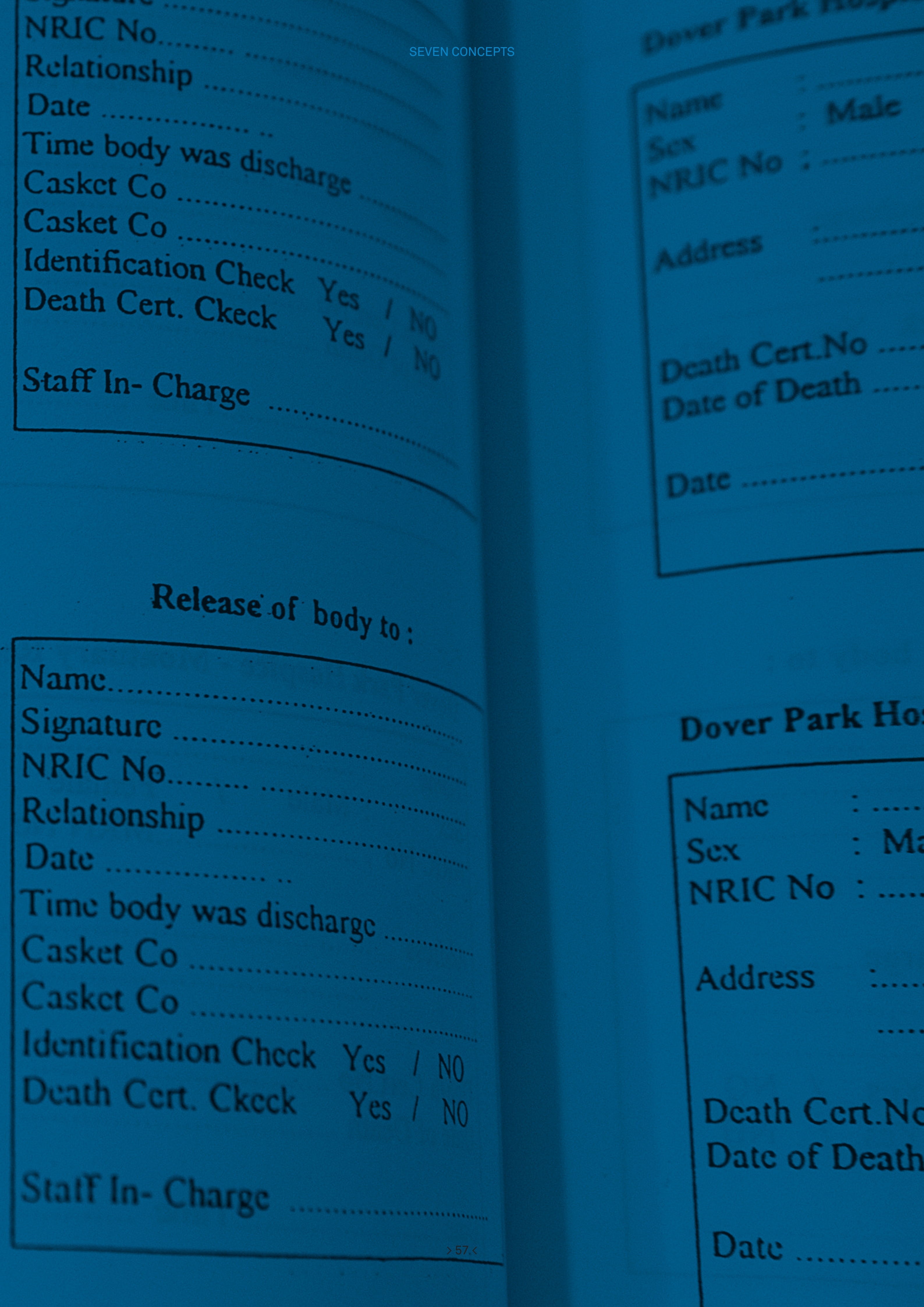
A COMPASS FOR THE END-OF-LIFE



Name
Sex : Male / Female
NRIC No
MRN No
Address
Death Cert.No
Date of Death
Date .... Time

Mortuary Register

Name :
Sex : Male / Female
NRIC No :
MRN No
Address :
Death Cert.No
Date of Death
Date .... Time



NRIC No................
Relationship ....
Date ....
Time body was discharge ....
Casket Co ....
Casket Co ....
Identification Check Yes / NO
Death Cert. Ckeck Yes / NO

Staff In- Charge ....

Release of body to :

Name.......................................
Signature ....
NRIC No...................................
Relationship ....
Date ....
Time body was discharge ....
Casket Co ....
Casket Co ....
Identification Check Yes / NO
Death Cert. Ckeck Yes / NO

Staff In- Charge ....

Dover Park Ho

Name : ....
Sex : Male
NRIC No : ....

Address : ....
....

Death Cert.No ....
Date of Death ....

Date ....

Dover Park Ho

Name : .....
Sex : Ma
NRIC No : .....

Address : .....
.....

Death Cert.No
Date of Death

Date ....

INSIGHTS

A COMPASS FOR THE END-OF-LIFE

DECISION-MAKING IS HIGHLY STRESSFUL FOR PATIENTS & FAMILIES

- Patients get stressed when they feel they are a burden to their family; financially, emotionally and physically.
- Care givers can educate and empower the patient and family to prepare for and navigate the end-of-life journey.
- Talking about money issues with families and patients is a sensitive subject for hospice teams.
- Staff try to break the collusion between family members, and reveal the voice of the patient.
- Patients don’t always feel empowered to communicate their needs and emotions; feeling grateful for care and not wanting to offend anyone.
- People trust doctors for advice more than nurses, especially if doctors manage their pain and show empathy and care.
- Loved ones can feel overwhelmed by the responsibility and sense of duty they have towards the patient, especially in the face of complex, urgent or critical decisions.
- Disintegrating family structures and mosaic lifestyles place additional pressure and challenges on any collective decision-making needed about end-of-life care and services.
- Families find ways to keep each other informed and updated about their loved one´s condition (facebook, email, phone) usually coordinated by the person who is the main care giver/visitor.

INCONSISTENT SERVICE EXPERIENCE

- A patient-centric service will be most beneficial but the main limitations are money and coordination.
- There is a role for a case manager to accompany patients in their journey and avoid ´medical homelessness.
- Teams behave inconsistently in their care delivery, making coordination and communication harder.
- The lack of knowledge of what funeral services entail, including expected costs, creates a lot of anxiety among families of the deceased.
- Technology is used to overcome time and distance problems that arise when multidisciplinary teams in different locations need to work together to deliver care (video conferencing, email photos, SMS).
- Doctors try to be more informal and intimate in palliative care, spending time with the patient to inform, reassure and encourage.

DISCONTINUOUS INFORMATION FLOWS

- Traditional healthcare hierarchies persist inside some hospices and can block effective information flow.
- Cultural and local language barriers exist between care givers, patients and loved ones preventing trust and intimacy.
- Care teams and families can help each other to keep well informed about the patients needs.
- The selection of a funeral home usually has to be done so quickly that it is mostly made by friends and family referrals.
- The national electronic patient record system is expected to make information flows smoother.
- Authenticity is essential in communication towards patients and loved ones.

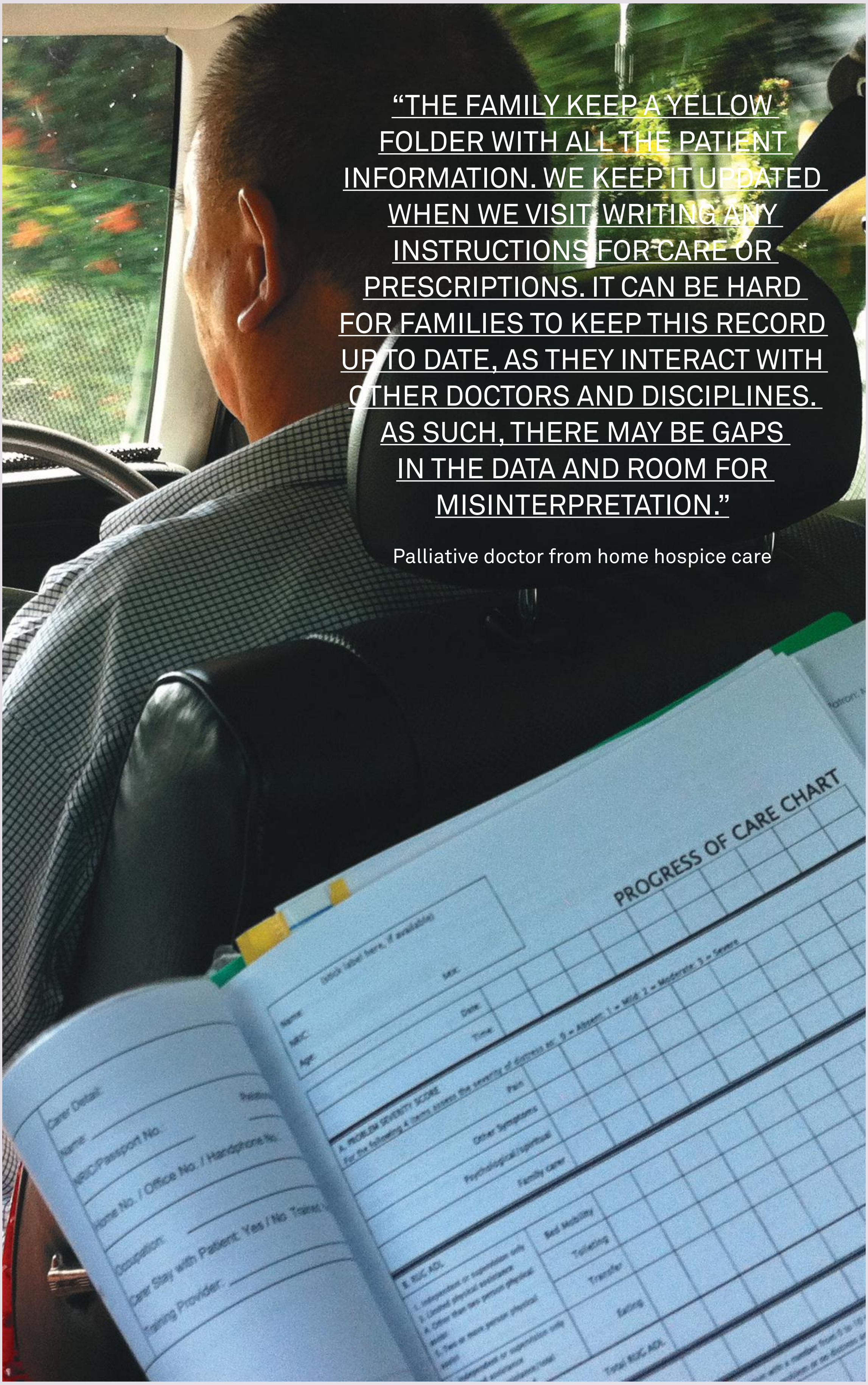
“PATIENTS AND FAMILIES NEED GUIDANCE TO TAKE THE RIGHT DECISIONS; TO KNOW WHAT IS IMPORTANT AND WHATIS NOT.”

Professor Cynthia Goh
Hospice Pioneer

Day care entrance where home care transfers to day care and where patients, their care givers and volunteers arrive for sessions.

A medical social worker counsels a patient´s wife as part of the hospice in-patient admission interview process.

The handover of families and the deceased from hospice to funeral service usually happens at the rear of hospice buildings, areas that are typically undesigned and serve as functional waste disposal and delivery points.



“THE FAMILY KEEP A YELLOW FOLDER WITH ALL THE PATIENT INFORMATION. WE KEEP IT UPDATED WHEN WE VISIT, WRITING ANY INSTRUCTIONS FOR CARE OR PRESCRIPTIONS. IT CAN BE HARD FOR FAMILIES TO KEEP THIS RECORD UP TO DATE, AS THEY INTERACT WITH OTHER DOCTORS AND DISCIPLINES. AS SUCH, THERE MAY BE GAPS IN THE DATA AND ROOM FOR MISINTERPRETATION.”

Palliative doctor from home hospice care

A COMPASS FOR THE END-OF-LIFE

COMPASS IS A PRODUCT-SERVICE PLATFORM THAT CREATES OPPORTUNITIES FOR END-OF-LIFE CONVERSATIONS AT KEY LIFE STAGES IN A NATURAL AND FRIENDLY WAY; SUPPORTING CITIZENS, PATIENTS, FAMILIES AND CARE PROFESSIONALS IN PREPARING FOR AND NAVIGATING THE END-OF-LIFE CARE LANDSCAPE. BY CONSIDERING DEATH AS A PART OF LIFE, COMPASS SEEKS TO NORMALISE END-OF-LIFE CONVERSATIONS AND FACILITATE PEOPLE TO MAKE IMPORTANT CHOICES WITH CONFIDENCE AND EASE. COMPASS ENSURES A CONSISTENCY IN SERVICE EXPERIENCE ACROSS PROVIDERS AND SETTINGS, FROM HOSPITAL TO CARE CENTRAL TO FUNERAL HOME. WITH COMPASS´ SUPPORT, TAKING IMPORTANT AND PERSONAL END-OF-LIFE CARE DECISIONS BECOMES A LESS ANXIOUS AND MORE EMPOWERING EXPERIENCE FOR PATIENTS AND THEIR LOVED ONES.

Having enough time to reach closure is important to reach a peaceful death, but is not always possible. Compass can be a good conversation starter that effectively wins time for people to prepare for their end-of-life.

The first three key life stages occur before a potentially terminal diagnosis, at moments in life when you naturally tend to be looking ahead and considering your future: during education, at 40 years old when you receive Eldershield extra insurance options and at retirement when you think about how you would like to spend your free time. During these life stages Compass touch points are outside of the healthcare sector - at school or university, at home or even within an insurance conversation.

The latter life stages follow on from a potentially life-threatening diagnosis, when Compass then becomes a tool to support palliative care team conversations with patients and their loved ones. In these stages Compass is designed to offer just the right balance of information based on the patient´s condition; not too little to be meaningless and not too much to be overwhelming and add anxiety.

In the final life stages of the end-of-life journey, when planning funeral services and navigating death care services Compass helps facilitate decision-making and ongoing bereavement support and counselling via the Care Central facility and services.

Compass takes the form of both digital technology as well as simple but tangible communication tools; for example there are several types of tool kit - with maps, applications, card sets, games boards - that serve as stimulus material to facilitate specific end-of-life conversations. The content reflects the services and support available in that particular Care Central and community. It is presented in an interactive and open format that people can naturally look at and discuss together with a trained professional, or as a team, a family or a group. Information is delivered in a timely manner, as and when people are ready to hear about the choices that they face at any given time.

In the Care Central, Compass takes the form of a Care Navigator. This is a new professional care giver role that offers patients and their loved ones a single point of contact to help them navigate through their care journey. Helping patients find information and determine what suits them best. This person helps offload patient communication tasks from the care team, allowing them to better focus on palliative care delivery. The role acts to complement and enhance the team-based palliative care approach a patient receives. By defining a Care Navigator role, this can help to raise and standardise the quality of basic palliative care delivery in a team. The Care Navigator gently hands over to a Funeral Care Navigator after the moment of death. They continue to assist loved

A COMPASS FOR THE END-OF-LIFE

1

COMPULSORY CARE VOLUNTEERING AS PART OF UNIVERSITY EDUCATION

Students receive care credit in addition to school credit as an integral part of their education. A university student can apply to become a Care Navigator and take care of an elderly hospice patient. During the period of caring, students will naturally raise the topic of end-of-life care and choices in class an with peers.

2

END-OF-LIFE CONVERSATION KITS TRIGGER PROACTIVITY AMONGST CITIZENS

The Compass Kits enable people to make conversations about end-of-life choices in various life stages and in an interactive way - individually, as a family or group. Compass Kits can be used in various life situations, such as taking out a mortgage, arranging insurance cover, facilitating a retirement planning conversation, as well as during bereavement support. The kits are designed to help people consider different future personal scenarios based on their own local services and situation.

3

INCLUDING END-OF-LIFE CONVERSATIONS IN INSURANCE PLANNING

Banks and companies can also get involved in end-of-life conversations as part of their corporate social responsibility. Insurance companies could use specific assessment tools, to determine the associated risks and costs of paying for specific end-of- life care plans for their customers. This would enable them to offer New Horizons as a services in their product range.

4

LAST MEAL EXPERIENCE IS AN INVITATION TO TALK ABOUT END-OF-LIFE ISSUES

Last Meal is a service available at either the Care Central cafe, funeral homes or selected restaurants in which the duration of a meal is used to raise and discuss end-of-life choices for couples, families and groups, all facilitated by a Care Navigator. A discount trial voucher is included in the New Horizons kit.

5

COOKING & CHATTING EVENT TO CASUALLY DISCUSS END-OF-LIFE CHOICES

Events such as the Cooking and Chatting event, organised and run by Care Central, could offer opportunities to discuss end-of-life care and options through an engaging and non-stigmatising programming.

6

CONSULTATION NAVIGATION AID FOR DOCTORS TO USE WITH THEIR PATIENTS

Compass Consult is a platform where care options and plans - curative and palliative - can be discussed between patients and doctors. At home, families can discuss care options, learning from others who have shared their own care experiences. The personal care maps allow families to discuss their preferences of care settings, carers, care processes and life-sustaining interventions.

7

HOME CARE KIT SUPPORTING FAMILIES TO CARE FOR THEIR LOVED ONES

Compass Home Care kit provides up to date, tailored information on how to best care for loved ones at home. During transitions from home-to-hospice the Compass service and Care Navigator can help patients / families / care teams to smoothen the transition between care settings.

8

FUNERAL DESIGNER ASSISTS PEOPLE IN DESIGNING THEIR IDEAL FUNERAL

Through the Compass user interface, patients can pre-configure their choices for their funeral. Necessary funding could be requested through their social network that can be released once the patient passes and loved ones activate the pre-configured funeral choice.

9

FUNERAL CARE NAVIGATOR PROVIDES BOTH PRACTICAL AND EMOTIONAL SUPPORT

The Care Navigator's role seamlessly continues through to funeral services provision; the Funeral Care Navigator interfaces with the hospice Care Navigator and will support the family from funeral through to bereavement phases.

10

BEREAVEMENT COUNSELLING OFFERED BY THE FUNERAL SERVICE PROVIDER IN PARTNERSHIP WITH CARE CENTRAL

Compass Bereavement support is offered by funeral services and could be hosted by the local Care Central, helping loved ones over time recover from their grief.

Studying

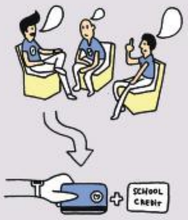
2

The Saying Goodbye kit offers families a easier way to discuss difficult topics such as the passing of a loved one

1

Compulsory care volunteering as part of university education

1



Students receive care credit in addition to school credit

Planning insurance

3

Insurance planning meeting, discussing long term plans and end-of-life choices

2

The New Horizons kit for insurance planning conversations.

4

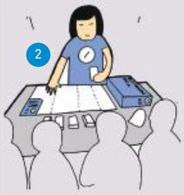
Last Meal restaurant offers facilitated end-of-life conversation for a duration of a meal

Retirement

5

Cooking & Chatting event to casually discuss end-of-life choices

2

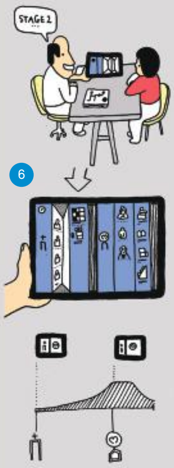


Retirement planning kit discussing care and end-of-life scenarios at the Care Central and home

2

Home Care Kit

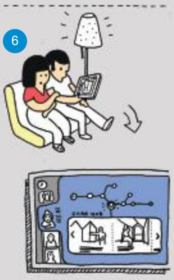
Diagnosis



6

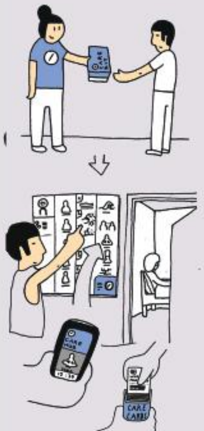
Consultation navigation aid for doctors to use with their patients

6



At home, families can discuss care options, learning from others care experiences

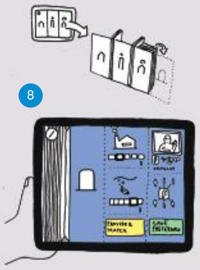
Hospice care



7

Home Care kit supporting families to care for their loved ones

8



Funeral planning application helps understand options clearly

Funeral care

8

Funeral designer assists people in designing their ideal funeral

Family can easily activate the funeral choice of their loved one

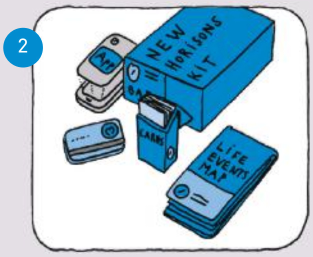
9

Funeral Care Navigator provides both practical and emotional support

Bereavement

10

Bereavement counselling offered by Care Central including creating the Life Book of a loved one as part of the counselling

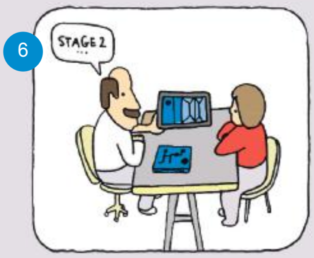


END-OF-LIFE CONVERSATION KITS TRIGGER PROACTIVITY AMONGST CITIZENS

HOME CARE KIT SUPPORTING FAMILIES TO CARE FOR THEIR LOVED ONES

INTRODUCE EARLIER TOUCHPOINTS TO CARE

consider that engagement with end-of-life and hospice services can begin from a young age and last throughout a lifetime to build a unique and personal service for any citizen.



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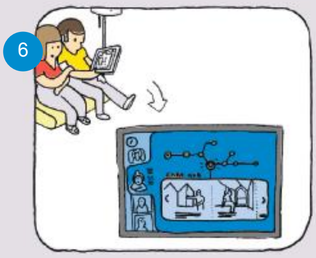

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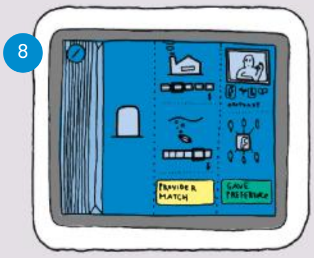

FUNERAL DESIGNER ASSISTS PEOPLE IN DESIGNING THEIR IDEAL FUNERAL

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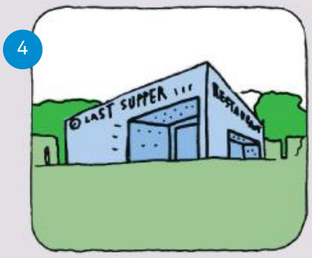
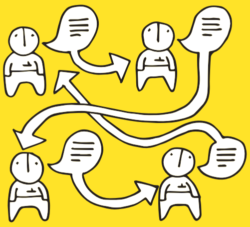


LAST MEAL EXPERIENCE IS AN INVITATION TO TALK ABOUT END-OF-LIFE ISSUES

COOKING & CHATTING EVENT TO CASUALLY DISCUSS END-OF-LIFE CHOICES

BEREAVEMENT COUNSELLING OFFERED BY THE FUNERAL SERVICE PROVIDER IN PARTNERSHIP WITH CARE CENTRAL

DIRECT COMMUNICATION BETWEEN STAKEHOLDERS



hospice services require many people to work together to deliver optimum care, so work on keeping people well informed and involved to ease communication and clarify both decision-making as well as create room for reflection.

FACILITATE PERSONALISATION OF CARE

define how far you can go to personalise your service considering different levels; through furniture or products you can offer, service training you can give your staff, the environments you can create in-house as well as the tone-of-voice of all your service communications.

GUIDE PEOPLE THROUGHOUT THEIR CARE JOURNEY

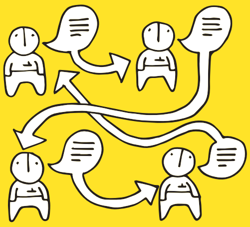
think about ways you can ´hold the hands´ of patients, loved ones and trainee care givers as they move through your service.

DESIGN WITH FAMILY IN MIND

loved ones travel the end-of-life journey with their patient and beyond into bereavement and their own end-of-life stage, they too have specific and important needs that should not be neglected or underestimated since they can enhance the experience of the patient.

CREATE A COHERENT CARE BRAND

define a visually iconic and consistent service identity that expresses itself at every touchpoint so that people become familiar with and trust the service and can better navigate along the end-of-life journey.



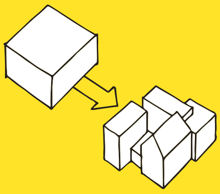
DIRECT COMMUNICATION BETWEEN STAKEHOLDERS

hospice services require many people to work together to deliver optimum care, so work on keeping people well informed and involved to ease communication and clarify both decision-making as well as create room for reflection.

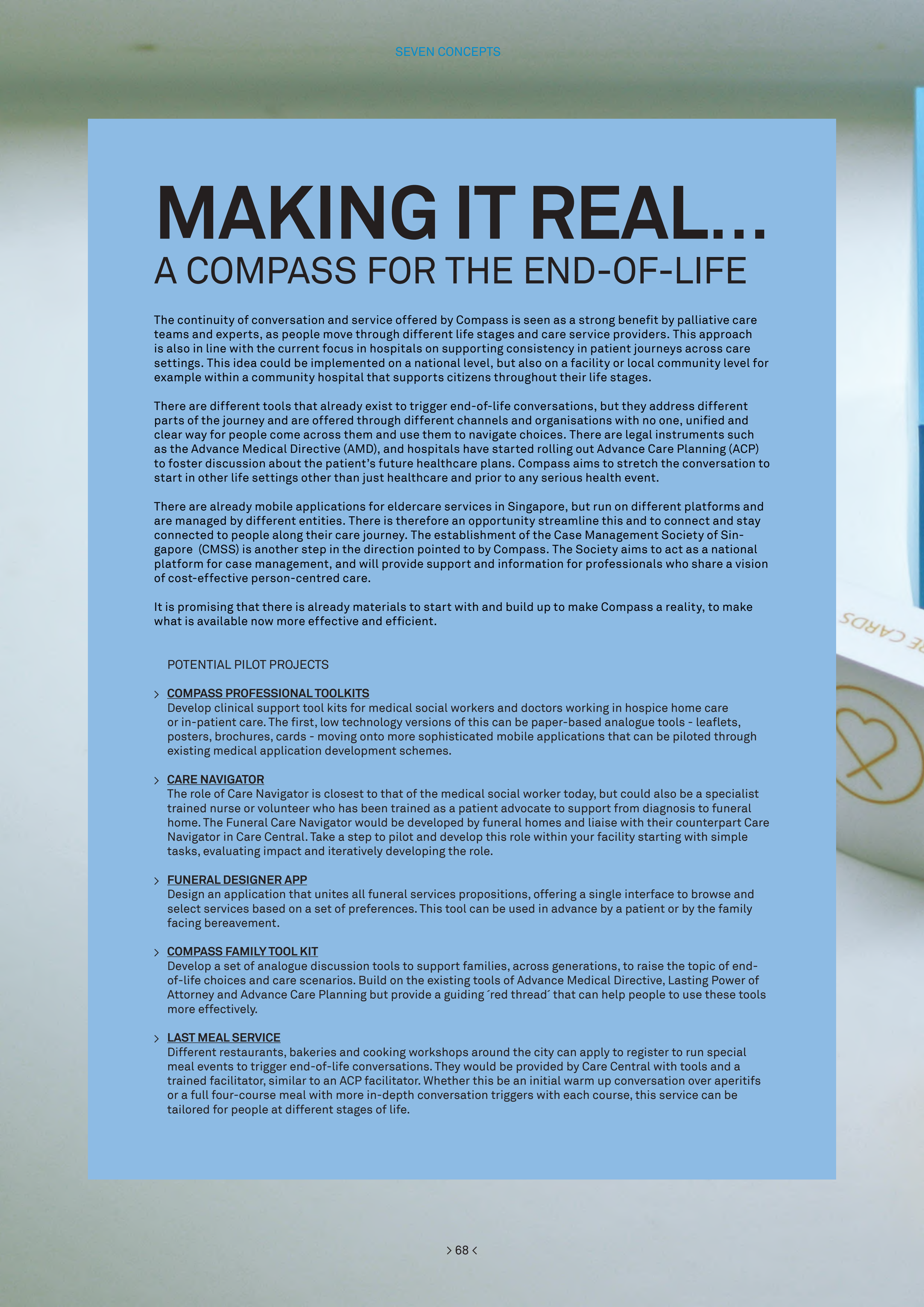
OPEN SERVICES TO WIDER PUBLIC

removing stigmas, fears and barriers to addressing end-of-life issues requires reaching everyday people in their everyday lives with interesting, relevant and accessible services.

AVOID THE INSTITUTIONAL



hospice care should clearly demarcate personal, attentive and high touch palliative care qualities, a step away from institutional care settings that tend to be anonymous and impersonal.



MAKING IT REAL…

A COMPASS FOR THE END-OF-LIFE

The continuity of conversation and service offered by Compass is seen as a strong benefit by palliative care teams and experts, as people move through different life stages and care service providers. This approach is also in line with the current focus in hospitals on supporting consistency in patient journeys across care settings. This idea could be implemented on a national level, but also on a facility or local community level for example within a community hospital that supports citizens throughout their life stages.

There are different tools that already exist to trigger end-of-life conversations, but they address different parts of the journey and are offered through different channels and organisations with no one, unified and clear way for people come across them and use them to navigate choices. There are legal instruments such as the Advance Medical Directive (AMD), and hospitals have started rolling out Advance Care Planning (ACP) to foster discussion about the patient's future healthcare plans. Compass aims to stretch the conversation to start in other life settings other than just healthcare and prior to any serious health event.

There are already mobile applications for eldercare services in Singapore, but run on different platforms and are managed by different entities. There is therefore an opportunity streamline this and to connect and stay connected to people along their care journey. The establishment of the Case Management Society of Singapore (CMSS) is another step in the direction pointed to by Compass. The Society aims to act as a national platform for case management, and will provide support and information for professionals who share a vision of cost-effective person-centred care.

It is promising that there is already materials to start with and build up to make Compass a reality, to make what is available now more effective and efficient.

POTENTIAL PILOT PROJECTS

- **COMPASS PROFESSIONAL TOOLKITS**
  Develop clinical support tool kits for medical social workers and doctors working in hospice home care or in-patient care. The first, low technology versions of this can be paper-based analogue tools - leaflets, posters, brochures, cards - moving onto more sophisticated mobile applications that can be piloted through existing medical application development schemes.

- **CARE NAVIGATOR**
  The role of Care Navigator is closest to that of the medical social worker today, but could also be a specialist trained nurse or volunteer who has been trained as a patient advocate to support from diagnosis to funeral home. The Funeral Care Navigator would be developed by funeral homes and liaise with their counterpart Care Navigator in Care Central. Take a step to pilot and develop this role within your facility starting with simple tasks, evaluating impact and iteratively developing the role.

- **FUNERAL DESIGNER APP**
  Design an application that unites all funeral services propositions, offering a single interface to browse and select services based on a set of preferences. This tool can be used in advance by a patient or by the family facing bereavement.

- **COMPASS FAMILY TOOL KIT**
  Develop a set of analogue discussion tools to support families, across generations, to raise the topic of end-of-life choices and care scenarios. Build on the existing tools of Advance Medical Directive, Lasting Power of Attorney and Advance Care Planning but provide a guiding ´red thread´ that can help people to use these tools more effectively.

- **LAST MEAL SERVICE**
  Different restaurants, bakeries and cooking workshops around the city can apply to register to run special meal events to trigger end-of-life conversations. They would be provided by Care Central with tools and a trained facilitator, similar to an ACP facilitator. Whether this be an initial warm up conversation over aperitifs or a full four-course meal with more in-depth conversation triggers with each course, this service can be tailored for people at different stages of life.


COMPASS HOME CARE KIT
Helping you to care for your loved ones, so you can focus on giving love!
COMPASS
health info
available services
YOUR CARE MAP
Compass Life Events Ma

BUILDING COMMUNICATION BRIDGES


Adm to Hospital
Hospice Adm

INSIGHTS

BUILDING COMMUNICATION BRIDGES

MULTIDISCIPLINARY CARE TEAMS ARE CHALLENGED TO STAY FULLY INFORMED

- There is a need for professional collaboration across disciplines with a clear clinician leadership.
- Teams find practical, ad hoc and low tech ways to collaborate.
- Professional language barriers need to be overcome between disciplines involved in palliative care.
- To build a holistic and complete picture of a person, the team relies on each others ears, eyes and hands.
- Technology tools helps teams to stay in touch, exchange information, ask questions and take care decisions in spontaneous ways in in-patient, day care and home care services.
- A clear chain of communication between professionals and across levels of responsibility helps teams coordinate care; this chain can also include family.
- Visual tools help teams communicate care issues across disciplines and develop better ways to work together.

DISCONTINUOUS INFORMATION FLOWS

- Traditional healthcare hierarchies persist inside some hospices and can block effective information flow.
- Cultural and local language barriers exist between care givers, patients and loved ones preventing trust and intimacy.
- Care teams and families can help each other to keep well informed about the patients needs.
- The selection of a funeral home usually has to be done so quickly that it is mostly made by friends and family referrals.
- The national electronic patient record system is expected to make information flows smoother.
- Authenticity is essential in communication towards patients and loved ones.

SHORTAGE OF PALLIATIVE CARE PROFESSIONALS

- Trial periods are needed to effectively evaluate if staff can perform a palliative care role.
- There is a shortage of doctors and nurses with the right qualifications, experience and attitude for palliative care.
- Pioneering hospice organisations are partnering to create training courses that will disseminate their practical knowledge and experience to develop the professionals required.
- Training palliative care givers involves building a deep empathy and respect for patients and families.
- Palliative professionals need to have an attitude of self-assessment and a desire to continuously improve in order to evolve the field.
- Palliative care givers need to be able to transfer their knowledge and train peers in order to scale up experienced professionals.
- Social workers are in short supply so in hospices they have to focus on the most needy cases.
- Finding hospice staff with the right mix of clinical skills, personality traits, the right attitude and right heart is extremely tough.
- Strong communication skills, verbal and non-verbal, are an important criteria in recruiting staff.
- Despite progress to raise the status of nurses in Singapore, it is generally still difficult to attract and retain good people in the profession, even more so in hospice care.

PALLIATIVE CARE TEAMS NEED TO BE CARED FOR

- Working in palliative care is seen as a meaningful professional experience that brings immense personal satisfaction.
- Due to the close interaction staff have with patients and families in moments of pain and suffering, they have to define clear personal boundaries to stay strong.
- Although staff stress is recognised by hospice management, current solutions do not seem to be working and resignation or sabbaticals are the only ways out.
- Even though impartial, off-site therapy services are offered to staff, many do not use the service in case they look as if they are failures.
- Staff try to make their own strategies to cope with the stress of an emotionally draining job, such as leaning on each other in the team.
- Young foreign nurses can suffer homesickness that unsettles them personally, forces them to stick together and detaches them from staff and patients.
- Staff build morale and a sense of togetherness by sharing food and meals together.

“HEALTHCARE TECHNOLOGY WAS FOR ADMINISTRATIVE WORK, BUT NOW MORE DOCTORS RECOGNISE ITS BENEFITS FOR CARE DELIVERY AND CLINICAL OUTCOMES, AND ARE PUTTING IT TO CLINICAL USE.”

Mr. Ken Tan
Managing Director, Pulsesync

A multidisciplinary care team meets to share and discuss their in-patient cases and decide on appropriate actions and learnings.

A volunteer GP uses his lunch break to attend ward rounds in the hospice with the nursing team.

A nurse at a hospice memorial service lights a candle of remembrance for her patients who have passed away.

A team of staff nurses and assistant nurses huddle at a hall table to complete paperwork for their patients.

“I CAN ALWAYS ESCALATE A PROBLEM TO MY SUPERIOR. I TALK TO HER 1-3 TIMES A WEEK TO UPDATE HER ABOUT ANY ISSUES ABOUT A PATIENT OR WITH STAFF.”

Senior nurse manager

BUILDING COMMUNICATION BRIDGES

PALLIAPP IS A COMMUNICATION TOOL FOR PALLIATIVE CARE PROFESSIONALS TO STAY IN TOUCH, EXCHANGE INFORMATION, SHARE BEST PRACTICE, ASK QUESTIONS AND SUPPORT COLLECTIVE DECISION-MAKING ACROSS MULTIPLE DISCIPLINES. IT CREATES A PALLIATIVE CULTURE OF CARE BY ORGANISING COMMUNICATION LINES, IN SPONTANEOUS WAYS, BETWEEN CARE GIVERS, AROUND THEIR PATIENTS RATHER THAN AROUND SEPARATE DISCIPLINES OR LOCATIONS. PROFESSIONAL COMMENTS ARE AGGREGATED AND INTEGRATED FROM DIFFERENT CARE GIVER PERSPECTIVES TO BUILD A HOLISTIC AND SHARED PICTURE OF EACH INDIVIDUAL PATIENT.

PalliApp acts as a direct communication service platform that would be compatible with the National Electronic Patient Record (NEPR) but does not in itself hold confidential patient health data. To safeguard the confidentiality of patient-related information and the liability of professionals using it, PalliApp acts as a communication tool within teams, and would not be accessible to patients and families. However, it would be unique in offering direct connections between the clinical care team (doctors, nurses, social workers, allied health professionals) and spiritual care givers and selected volunteers. There would be different levels of access to the communication network depending on each professional´s relationship to the patient at a given time.

PalliApp has two main features: PalliApp Pro is a ´back office´ feature only for palliative professionals and it supports their continuous professional training and education. Whilst PalliApp Care offers professionals an overview of their past and present patients and the chance to communicate directly with other members of the care team around each patient - scheduling impromptu meetings when a patient has an incident, posting agenda points to cover in the weekly multidisciplinary meeting or sending a short message to a team member.

The PalliApp interface is visual and graphical in its representations of care networks, making it easy-to-use and approachable, even for technophobes. Simple menus that are not too deep to navigate through, mean productivity is not jeopardised but rather enhanced. Intuitive and quick ways are offered to gather team opinions and access the most up to date patient-related comments at a glance. Such new technology tools can help to position palliative care as a dynamic area of healthcare, attractive to younger generations of professionals.

BUILDING COMMUNICATION BRIDGES

1 THE CARE NAVIGATOR HELPS FAMILIES TO SET UP THE CARE NETWORK OF THEIR LOVED ONES

A Care Navigator can help the family to set-up the care giver network around the patient using the PalliApp bridge builder. WIth this a family has a personalised view on the wider care team taking care of their loved one, including any family or friends, spiritual representatives and even their own GP.

2 PALLIAPP FACILITATES THE SPONTANEOUS ´HUDDLING´ OF THE CARE TEAM TO CONFER ABOUT A PATIENT

Smaller units of multidisciplinary care team - doctor, staff nurse, social worker, allied health professional - are organised around specific patients. They may need to confer quickly or ´huddle´together during their shift to take care planning decisions or discuss a patient´s changing needs.

3 PALLIAPP HELPS TO AVOID GAPS IN PATIENT CASE NOTES AS THEY MOVE BETWEEN HEALTHCARE SERVICES

If a recently discharged or home care patient is admitted urgently to the local Emergency Department PalliApp is able to transfer the attending clinician's comments and actions to the palliative care team. This relieves the family from having to keep their copy of the patient file updated and avoids gaps in the case notes. It also prepares Care Central for any subsequent emergency admissions required.

4 THE PALLIAPP ALERTS PROFESSIONALS ABOUT THEIR PATIENT'S STATUS

PalliApp provides doctors with an overview of all patients who they are currently treating, or have previously treated. The information and care network is organised around the patient, pushing notifications and alerts to the care team about patient-related events, changes in condition and potential forthcoming challenges.

5 THE PALLIAPP PRO ALLOWS PROFESSIONALS TO SHARE AND DISCUSS CASES

PalliApp Pro is a ´clinical back office´communication tool that enables the wider palliative care network and professionals to share and discuss cases amongst themselves to enhance the holistic view on patients and foster knowledge sharing and a culture of learning.

6 THE PALLIAPP AS A PROFESSIONAL AWARD PLATFORM

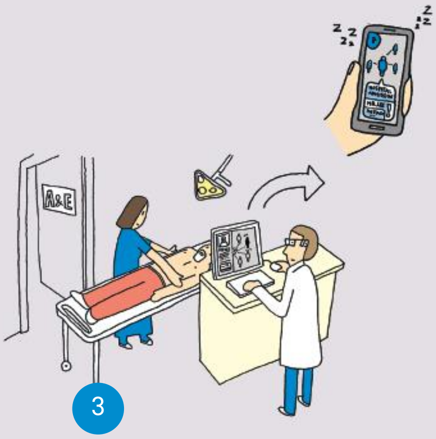
Leveraging their professional network, palliative professionals can choose the ´Best Palliative Professional of the Month / Year´. Aside from peer recognition, this professional will receive time and funding to be able to coach 10 other palliative care professionals over a period of time to disseminate and scale up best practices.


SHARE
CARE NETWORK CONFIGURATOR

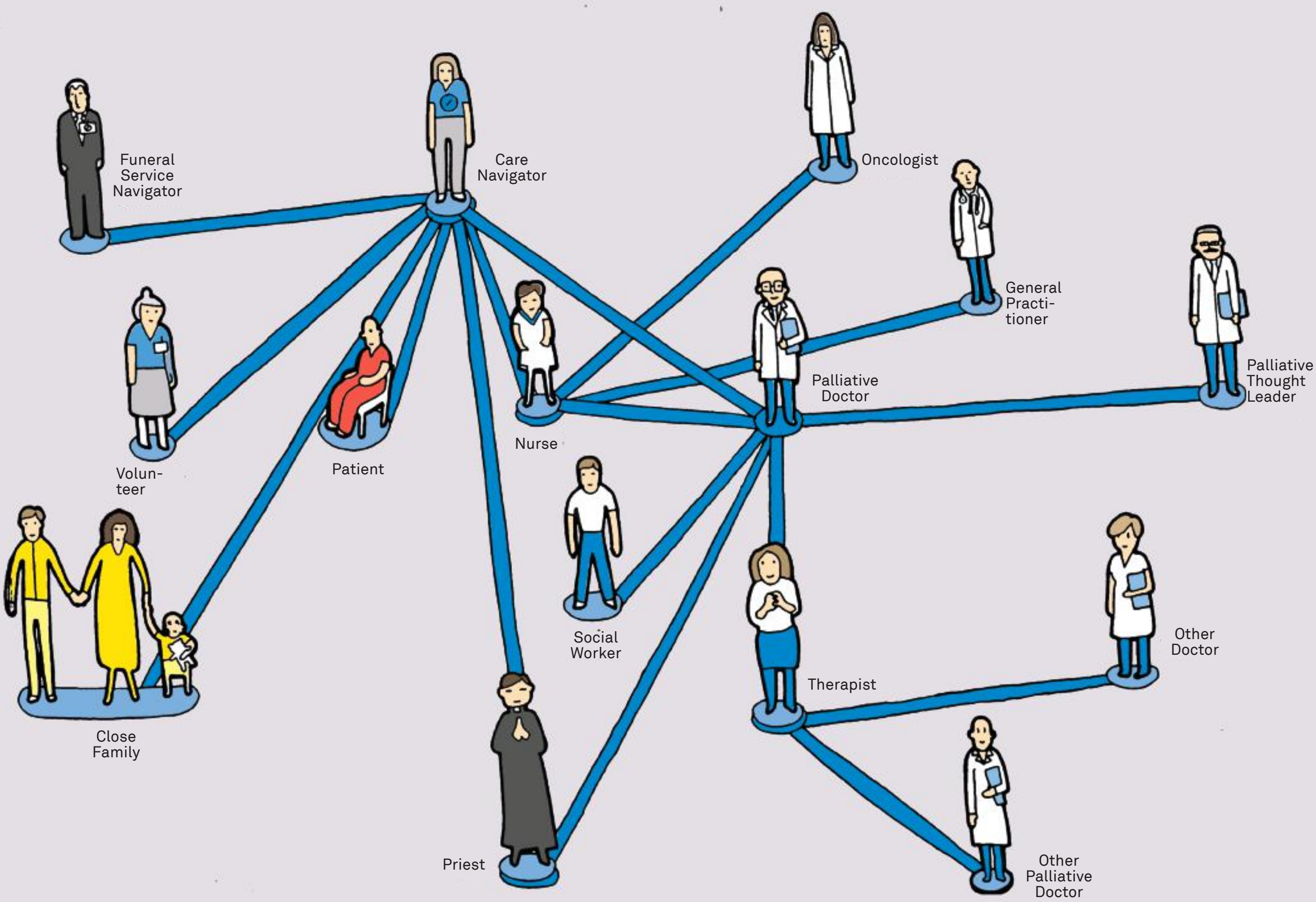
1

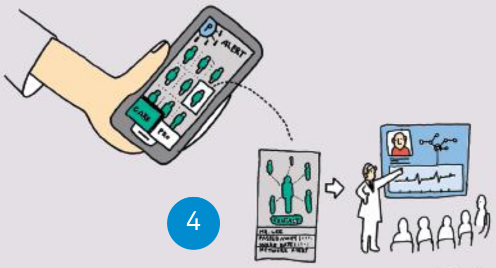

DR. WOO
TEAM MORRIS
11.20

2

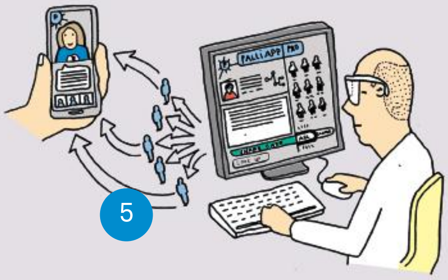

A&E

3

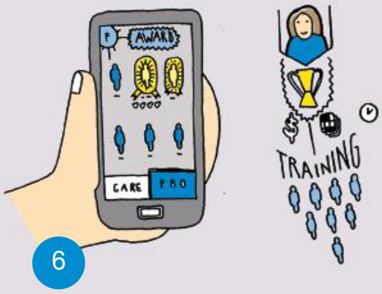

Funeral Service Navigator
Care Navigator
Oncologist
General Practi-tioner
Palliative Thought Leader
Palliative Doctor
Nurse
Volun-teer
Patient
Social Worker
Close Family
Therapist
Other Doctor
Priest
Other Palliative Doctor


ALERT
CARE
PRO

4


PALLI APP PRO

5


AWARD
CARE
PRO
TRAINING

6

3

PALLIAPP HELPS TO AVOID
GAPS IN PATIENT CASE NOTES
AS THEY MOVE BETWEEN
HEALTHCARE SERVICES

1

THE CARE NAVIGATOR HELPS
FAMILIES TO SET UP THE CARE
NETWORK OF THEIR LOVED ONES

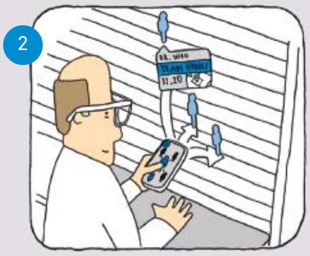
5

THE PALLIAPP PRO ALLOWS
PROFESSIONALS TO SHARE
AND DISCUSS CASES

6

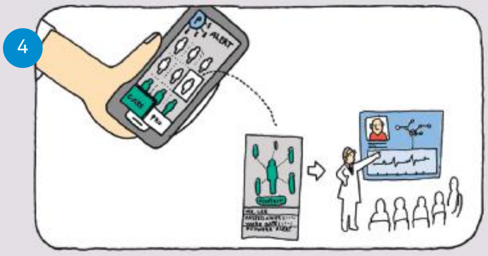
THE PALLIAPP AS A
PROFESSIONAL AWARD
PLATFORM

2



PALLIAPP FACILITATES THE
SPONTANEOUS ´HUDDLING´ OF
THE CARE TEAM TO CONFER
ABOUT A PATIENT

4



THE PALLIAPP ALERTS
PROFESSIONALS ABOUT THEIR
PATIENT’S STATUS

INTRODUCE EARLIER TOUCHPOINTS TO CARE

consider that engagement with end-of-life and hospice services can begin from a young age and last throughout a lifetime to build a unique and personal service for any citizen.

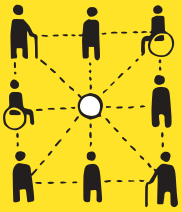
RECOGNISE THE PERSON BEHIND THE PATIENT

palliative care is holistic so patients must be taken care of beyond their disease, but with attention given also to the context of their lifestyle, their unique family set up, personal capabilities and beliefs.

FOSTER A CULTURE OF LEARNING IN CARE

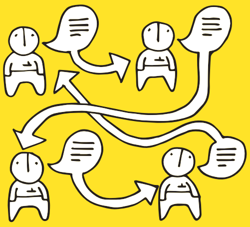
develop mechanisms for teams to share, reflect, learn and apply their knowledge to promote and progress the palliative care profession as a whole, attract the best professionals and make hospices feel like great places to work.

PROVIDE ACCESSIBLE CARE



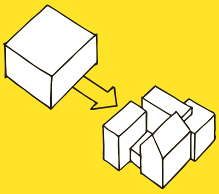
design services to feel as if they lie on people´s path, on their doorstep, within their reach - both physically as well as virtually.

DIRECT COMMUNICATION BETWEEN STAKEHOLDERS



hospice services require many people to work together to deliver optimum care, so work on keeping people well informed and involved to ease communication and clarify both decision-making as well as create room for reflection.

AVOID THE INSTITUTIONAL



hospice care should clearly demarcate personal, attentive and high touch palliative care qualities, a step away from institutional care settings that tend to be anonymous and impersonal.

MAKING IT REAL…

BUILDING COMMUNICATION BRIDG-

Singapore is in the process of implementing and rolling out a National Electronic Patient Record and connectivity in healthcare will be the norm. Confidentiality of patient information and professional liabilities will be an essential consideration.

Technophobia does exist, particularly in older generations of care professionals; it can seem overwhelming to have to incorporate a new technology tool into daily clinical practice. Younger generation professionals on the other hand feel it is quite natural and normal to be connected through social media communication channels to their network - personal or professional.

POTENTIAL PILOT PROJECTS

TRAINEE TEST BED

- Young student doctors and nurses studying in medical school or training in palliative care settings can be a potential target group with whom to pilot, test and develop PalliApp. They are more open to experiment and can act as demonstrators of this technology to speed adoption and transfer to the older generation of clinical care givers.

SIMPLE START UP

- Think about who might be the first, smaller, useful nodes to connect via PalliApp, e.g. palliative doctor to medical social worker. Simplifying the network allows easier and more controlled trial and test opportunities; first connect stakeholders inside a hospice team, then connect all stakeholders along the patient journey across organisations, then connect clinical and non-clinical stakeholders from different communities

STAR PRACTICE

- Simplify PalliApp by focusing in on the reward and training feature alone and applying this inside one closed palliative care community. Relevant contents are already being developed in Singapore with a best practices case book for palliative care doctors being created as a shared teaching and learning resource, to promote collaboration, openness and bring relief. PalliApp can make this content interactive and place it directly into the hands of practitioners.

Mr. Oliver Goh
Medisave: 0120 34267 27000
Ref: 01-26127

Care type: Inpatient
Facility: Geylang Care Hub
Medical Record Connect

CARE MARKET-PLACE

INSIGHTS

CARE MARKETPLACE

EXISTING FUNDING SOURCES CANNOT SERVE RISING DEMAND

- Finding viable and sustainable funding models for hospice care is a major challenge that is being met by hospices with ad hoc creative solutions.
- People, and middle class families in particular, cannot afford hospice care and are anxious about associated costs.
- Opportunities exist to streamline and balance cost with quality of care delivery in hospices.
- Many private insurances do not currently cover hospice or terminal care.
- Hospices face funding constraints, which mean that they have to prioritise care to specific groups: elderly and those with terminal chronic diseases.
- Hospices rely heavily on fundraising to fill the government subsidy gap, yet fundraising events are too predictable and are becoming less effective to meet a rising fundraising target.
- Encouraging volunteer programs can help fill a gap in resource shortages since they represent a free workforce for hospices, sometimes even being trained to attend to basic nursing tasks.

LACK OF UNDERSTANDING ABOUT PALLIATIVE CARE

- Palliative care is relatively new in Singapore.
- There is a need for champions and role models in palliative care.
- The healthcare system is more medically-centric than socially-centric.
- There is widespread ignorance about palliative care across Singapore society at all levels.
- It is important to expose healthcare professionals to hospice work as part of their standard training.
- Demonstration is more powerful than verbal explanation to communicate a hospice care principles to staff in training.

DEATH IS A TABOO SUBJECT

- Talking about death differently helps people behave differently at the end of life.
- If death is a societal conversation, people would be equipped to coach themselves through the journey.
- People don´t want to talk about death, they don´t have the courage.
- Hospice staff gradually reveal the truth to patients or families when they think they are ready.
- It is not death itself we fear but the moments before.
- Past practices dictate current mindsets. These include not leaving a dead relative alone, arranging a funeral in the shortest time possible and providing the best, are seen as signs of respect and love from relatives to the deceased.

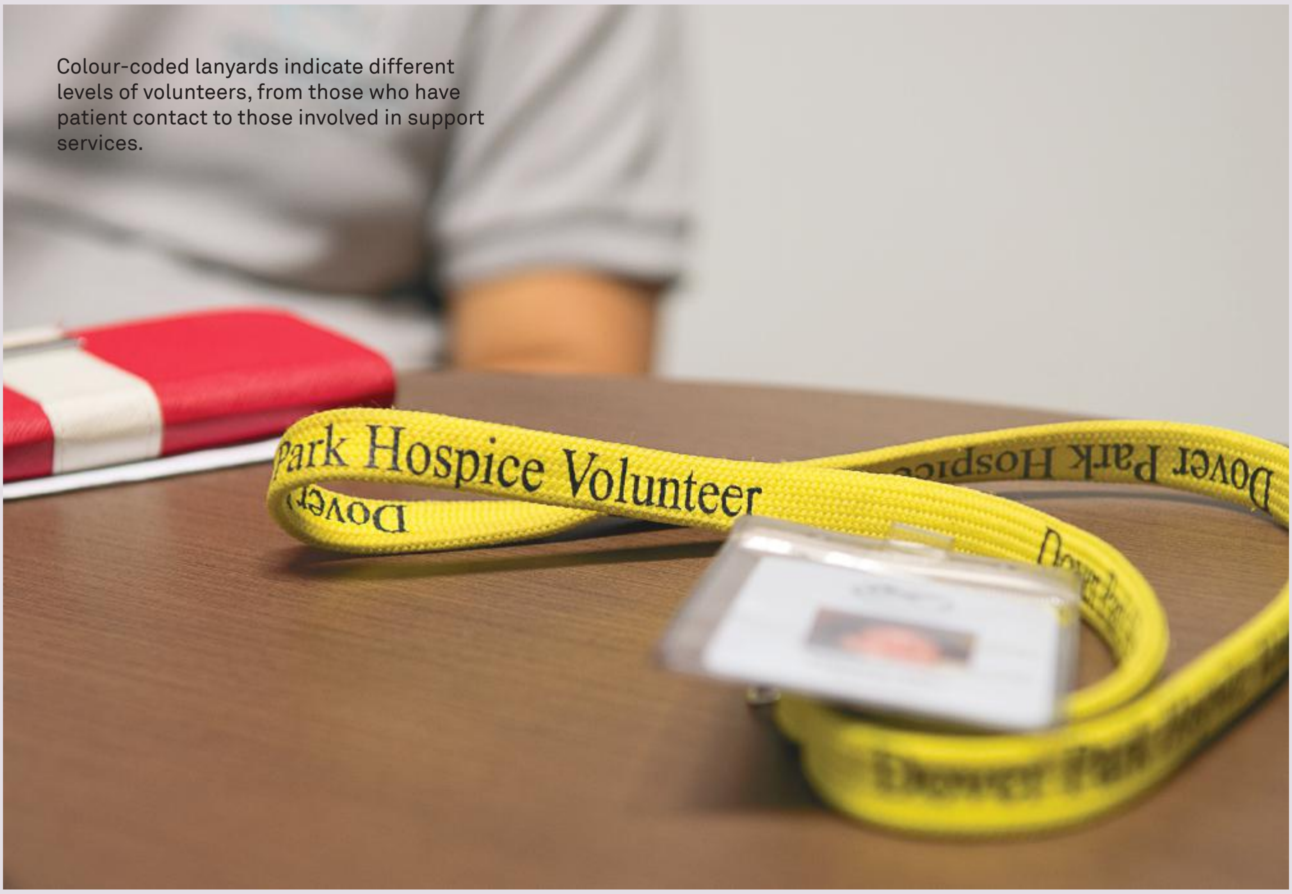
INCONSISTENT SERVICE EXPERIENCE

- A patient-centric service will be most beneficial but the main limitations are money and coordination.
- There is a role for a case manager to accompany patients in their journey and avoid ´medical homelessness.
- Teams behave inconsistently in their care delivery, making coordination and communication harder.
- The lack of knowledge of what funeral services entail, including expected costs, creates a lot of anxiety among families of the deceased.
- Technology is used to overcome time and distance problems that arise when multidisciplinary teams in different locations need to work together to deliver care (video conferencing, email photos, SMS).
- Doctors try to be more informal and intimate in palliative care, spending time with the patient to inform, reassure and encourage.

“RECOGNISING DEATH AS THE END POINT OF LIFE ALLOWS US TO LIVE LIFE FRUITFULLY.”

Ang Ziqian,
Founder of Ang Chin Moh Foundation

Volunteers and staff from the hospice gather together for a fundraising cycle race.



Colour-coded lanyards indicate different levels of volunteers, from those who have patient contact to those involved in support services.

A casket show room at a funeral service provider.

“THERE WERE A LOT OF THINGS TO ARRANGE WITH MY WIFE´S FUNERAL BUT I´VE DONE THIS MANY TIMES FOR SENIORS IN MY CHURCH COMMUNITY AND CARRY THIS FUNERAL SERVICE CARD WITH ME IN MY WALLET.”

Widower of a hospice patient

CARE MARKETPLACE

THE **CARE MARKETPLACE** IS AN OUTREACH PLATFORM FOR MATCHING VOLUNTEER SKILLS AND TIME, TO THE RESOURCE NEEDS OF CARE CENTRAL. IN THIS WAY IT ATTRACTS PEOPLE TO CONTRIBUTE TO AND DRAW UPON A RANGE OF CARE SERVICES IN THEIR COMMUNITY THROUGHOUT THEIR LIFE, FROM YOUTH TO DEATH. IT ENCOURAGES AND PROMOTES VOLUNTEERISM AND COMMUNITY ENGAGEMENT IN CARE, WHILST RAISING THE PROFILE AND EXTENDING THE REACH OF PALLIATIVE CARE WITHIN THE HEALTH SYSTEM. SOFTCARE DESCRIBES A NEW TYPE OF CARE THAT SHARES THE SAME HOLISTIC QUALITIES OF PALLIATIVE CARE, BUT THAT CAN BE RELEVANT BEFORE END-OF-LIFE. IT COMPLEMENTS THE CLINICAL CARE THAT PEOPLE RECEIVE THROUGHOUT THEIR LIFE. SOFTCARE CREDITS CAN BE GAINED AND SPENT BY ENGAGING IN THE CARE MARKETPLACE.

Each Care Central would be able to tailor the marketplace program to suit its own particular service focus, voluntary resource requirements and organisational service culture. This would mean that Care Centrals could best attract the right profile of volunteer for the right set of services they would like to offer; matching people to activities and tasks that can be both offered in, as well as provided by, a local Care Central.

For example, a student who is selected as suitable to volunteer in the Care Central as part of their university requirement, can earn credits to spend on wellness spa services offered there. A taxi driver can offer a couple of hours each week to transport patients, home care teams or loved ones in return for saving up care credits to use if he or his family face an end-of-life situation.
Finally, Care Marketplace has the potential to act as a means of achieving a more civic society, instilling a sense of personal responsibility into people and engaging ordinary citizens in serving their local communities. To foster this ´pay it forward´ mentality and encourage better social cohesion, community spirit, a sense of pride and belonging.

Additionally, by engaging in the Care Marketplace citizens become aware of end-of-life issues earlier, are more likely to be proactive and therefore better prepared for the choices they and their loved ones might face. Today´s Care Central volunteer could become tomorrow´s Care Central patient.

CARE MARKETPLACE

1 COMPULSORY VOLUNTEERING DURING UNIVERSITY

University students will be involved with Care Central in volunteering as Care Navigators as part of their studies. With this they can start earning Care credits into their Softcare credit pool.

2 CARE DISCOUNT COUPONS

Various service providers can become part of the Softcare scheme, to be able to provide Softcare-approved care for the community. These service providers can offer discounts and coupons for people to spend their Softcare credits with them.

3 TRANSPORT VOLUNTEERING FOR HOME HOSPICE SERVICES

Businesses can offer part of their operations, or time of their employees to support the Care Central in certain logistics of care delivery. For example, if taxi drivers volunteer and offer some hours of free transportation for patients and care teams in support of home hospice care, they can earn themselves Care credits.

4 CARE WORKER CARE CREDIT AWARD

Care workers can receive Care credit awards from satisfiled patients or loved ones. These Care credits will add to the their own Softcare credits for the long term.

5 CARE COMPANION

A diabetic person can volunteer to care for an elderly lady from Care Central, in return they are invited to complementary care at Care Central for help them manage their own health condition.

6 FRIENDS NETWORK CARE FUND

Friends can have a mutual agreement to merge their Care credit funds, and together create a closed care network to fund their own or a loved ones´care as a collective.

7 MICRO-CARE FUNDING FROM FRIENDS NETWORK

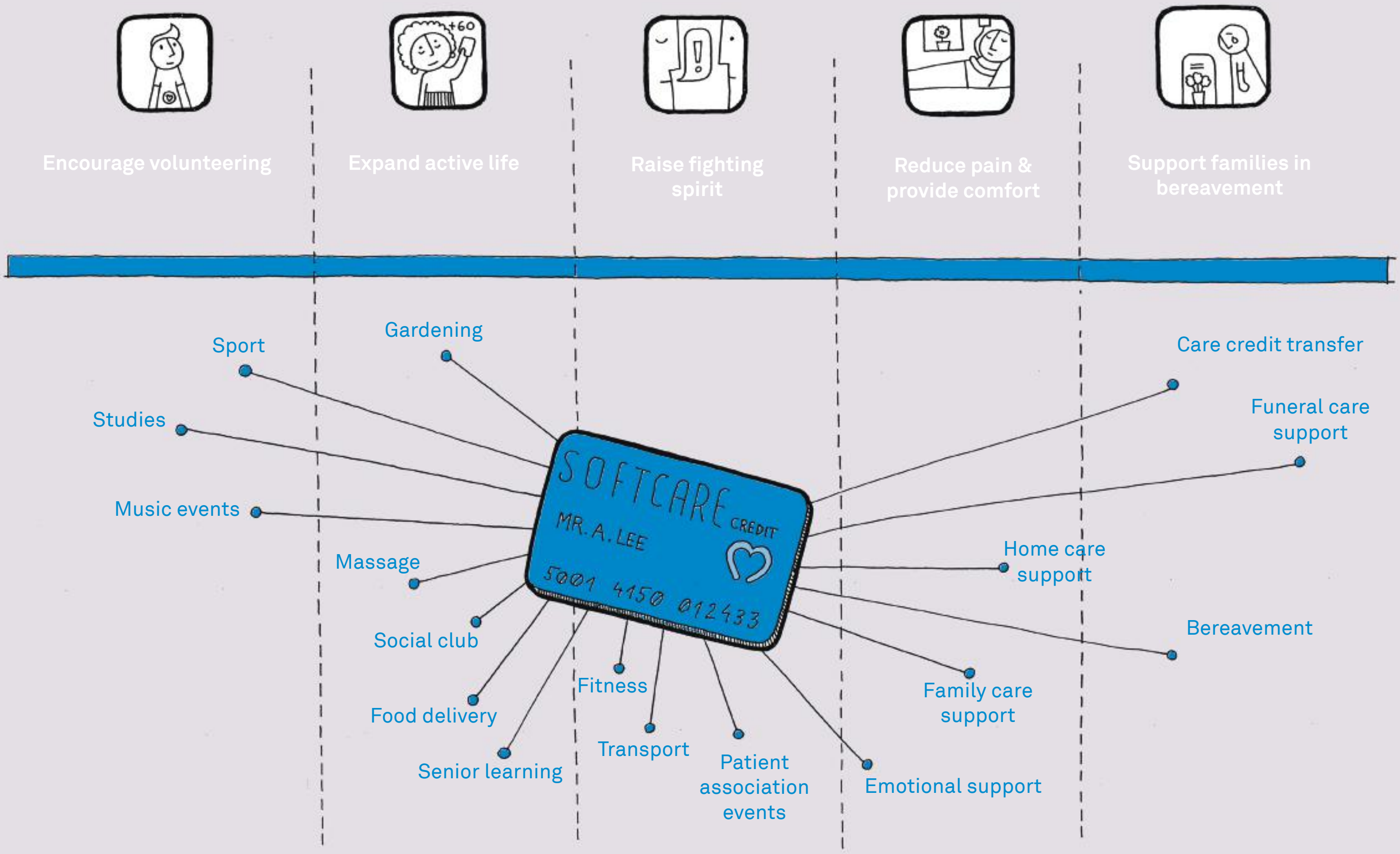
Through social network websites, patients and family can collectively save Care credit funds for end-of-life care and related expenses.

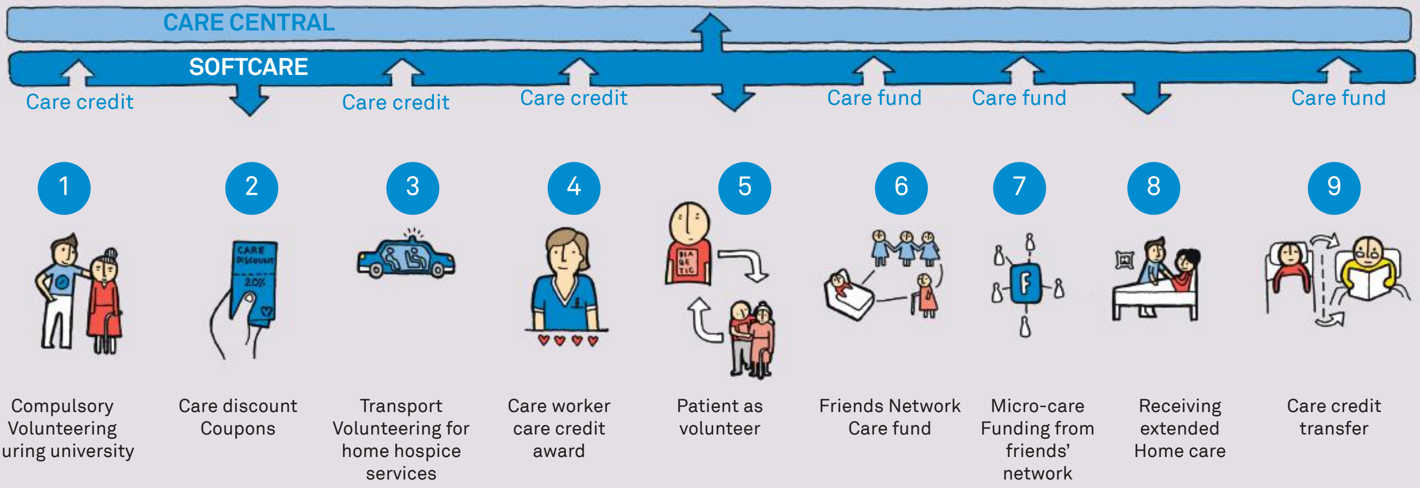
8 RECEIVING EXTENDED HOME CARE

Care credits can be used to pay for enhancements in home help and support, to be able to stay at home as long as possible. This help can be arranged via the Care Central volunteer marketplace or Care Central hospice home care services.

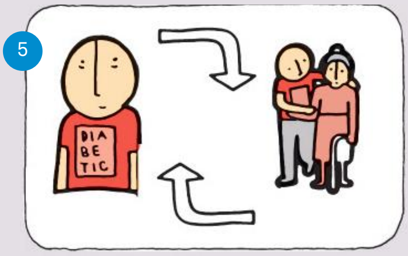
9 CARE CREDIT TRANSFER

Care Central patients can decide to transfer their Care credit in their will to another patient within the community.


Encourage volunteering
Expand active life
+60
Raise fighting spirit
Reduce pain & provide comfort
Support families in bereavement
Sport
Gardening
Studies
Music events
Massage
Social club
Food delivery
Senior learning
Fitness
Transport
Patient association events
SOFTCARE CREDIT
MR. A. LEE
5001 4150 012433
Care credit transfer
Funeral care support
Home care support
Bereavement
Family care support
Emotional support


CARE CENTRAL
SOFTCARE
Care credit
Care credit
Care credit
Care fund
Care fund
Care fund
1
Compulsory Volunteering during university
2
CARE DISCOUNT
20%
Care discount Coupons
3
Transport Volunteering for home hospice services
4
Care worker care credit award
5
Patient as volunteer
6
Friends Network Care fund
7
F
Micro-care Funding from friends' network
8
Receiving extended Home care
9
Care credit transfer

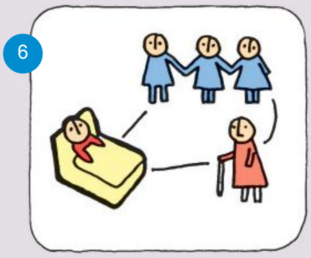
COMPULSORY
VOLUNTEERING DURING
UNIVERSITY



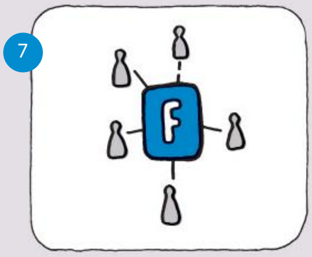
CARE COMPANION

MAKING VOLUNTEERING VISIBLE AND ATTRACTIVE

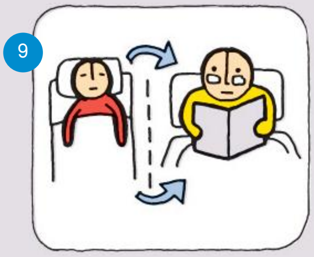
raise the profile of volunteers and encourage civic participation and the notion of ´giving back´ to the community to vitalise your hospice services.



FRIENDS NETWORK
CARE FUND

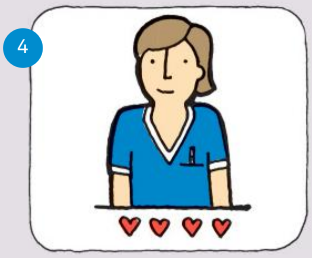


MICRO-CARE FUNDING FROM
FRIENDS NETWORK



CARE CREDIT TRANSFER

CARE DISCOUNT COUPONS



CARE WORKER CARE CREDIT
AWARD

FOSTER A CULTURE OF LEARNING IN CARE

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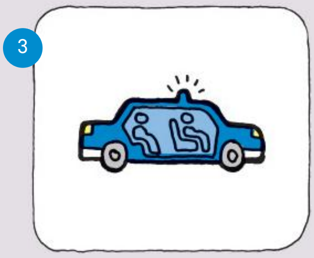


TRANSPORT VOLUNTEERING
FOR HOME HOSPICE SERVICES

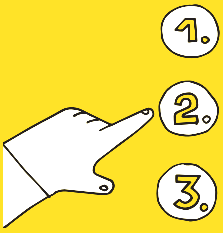
DON'T SEPARATE THE SICK FROM THE HEALTHY

removing stigma around end-of-life and hospice services means treating all people equally, in the face of illness.

INTRODUCE EARLIER TOUCHPOINTS TO CARE

consider that engagement with end-of-life and hospice services can begin from a young age and last throughout a lifetime to build a unique and personal service for any citizen.

EMPOWER PATIENTS WITH A SENSE OF CONTROL



end-of-life fears revolve around a sense of lost control over one´s life, so providing simple ways to regain that sense of control can help to focus and steady a person in their end-of-life journey.

FACILITATE PERSONALISATION OF CARE

define how far you can go to personalise your service considering different levels; through furniture or products you can offer, service training you can give your staff, the environments you can create in-house as well as the tone-of-voice of all your service communications.

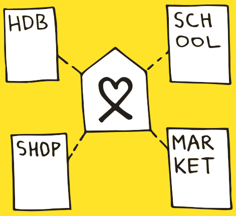
FOCUS ON THE LITTLE PLEASURES OF LIFE

create moments for people to celebrate life throughout your hospice program and space, to enjoy as much as possible the last days, weeks or months of life.

OPEN SERVICES TO WIDER PUBLIC

removing stigmas, fears and barriers to addressing end-of-life issues requires reaching everyday people in their everyday lives with interesting, relevant and accessible services.

BUILD NEIGHBOURHOOD CARE COMMUNITIES



discover ways to harness the power of crowds, leverage the natural behaviour and dynamics of communities to foster a more sustainable model of care enhancing the hospice service itself.

MAKING IT REAL…

CARE MARKETPLACE

Singapore is engaged in a timely debate, as is much of the developed world, as to how to fund long term care using combinations of government and private insurance schemes. This concept recognises the fact that existing schemes need to be supplemented to meet demand, but offers civic responsibility as a new motivational driver. Similar mechanisms already exist with parents volunteering at their children´s school to gain credits for admission, or citizens contributing to their local community to benefit from housing grants.

Care Marketplace could be implemented directly at an individual hospice facility level. This would help define a viable ´currency´ of Softcare credit; volunteering to the local Care Central can be offset against available services to enjoy at the Care Central. To scale up and roll out a Softcare credit ecosystem across the hospice care sector, for example, via Singapore Hospice Council or even via national savings plans, remains extremely bold and challenging. The concept is a trigger for rethinking possible funding mechanisms since today´s means will not fulfill future service demand.

POTENTIAL PILOT PROJECTS

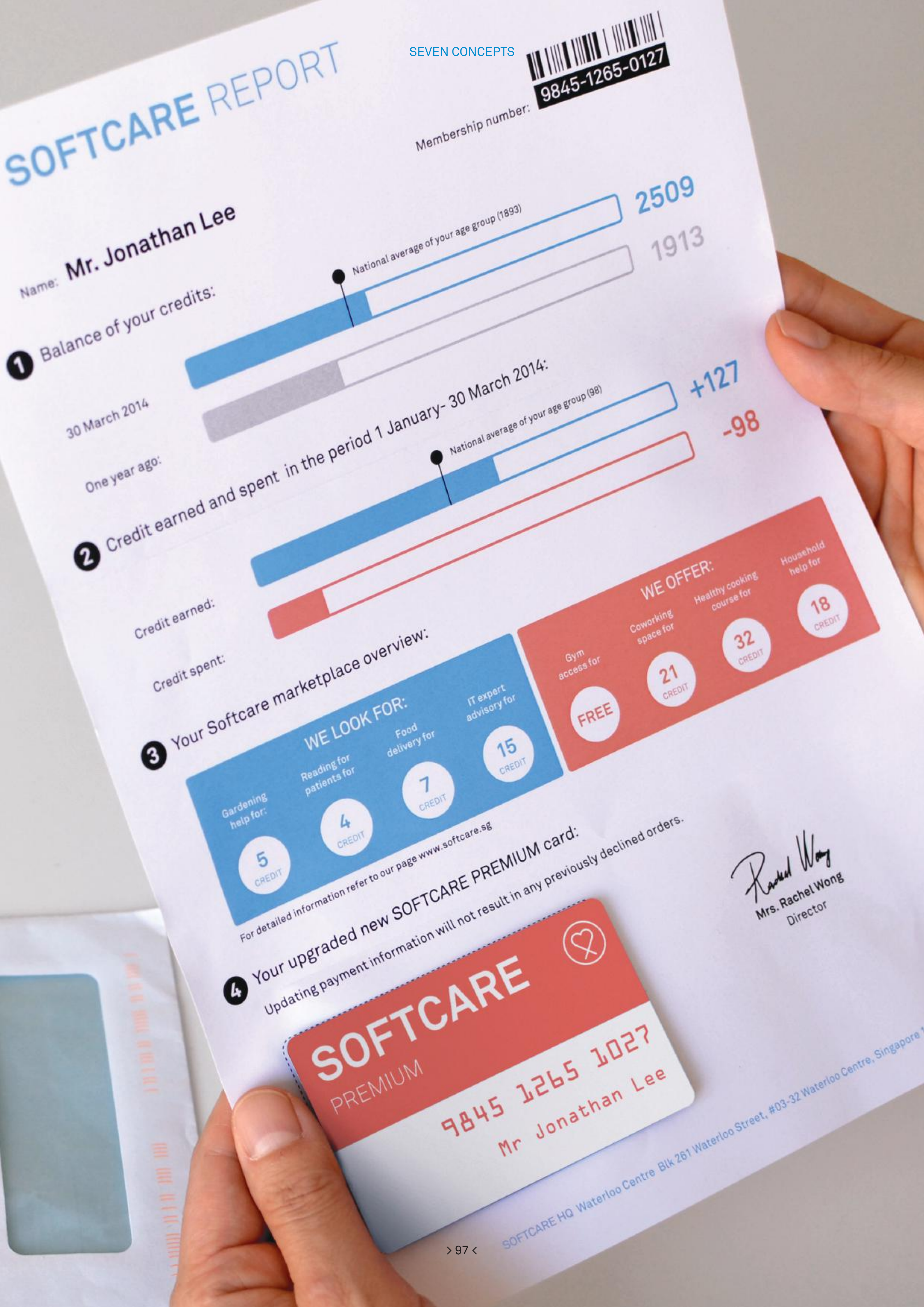
SOFTCARE CREDIT

- Consider what can be meaningful exchange for people in return for their volunteering efforts. Volunteers are already being offered skills training courses after they have reached a certain number of hours volunteered. Think of this idea as an enhancement of existing volunteer programs that are being established in some hospices.

FORMALISE COMMUNITIES

- Set up a Care Marketplace by formalising the hospice´s needs in terms of well-described and well-communicated volunteer activities and tasks. Communicate and build the volunteer marketplace in a way that will bring people naturally into the hospice through services they might enjoy and find appealing. Consider creating a community manager to curate and facilitate the conversation via the hospice website, events and campaigns in the local neighbourhood.

- **URBAN INTERVENTION**
  Look to social media communication campaigns and urban interventions to reach people beyond the boundaries of the hospice domain. Reach out to a wider community in the neighbourhood. Consider building upon existing or new IT infrastructure to support the softcare credit system.



SOFTCARE REPORT

Membership number: 9845-1265-0127

Name: **Mr. Jonathan Lee**

❶ Balance of your credits:

30 March 2014	National average of your age group (1893)	2509
One year ago:		1913

❷ Credit earned and spent in the period 1 January- 30 March 2014:

Credit earned:	National average of your age group (98)	+127
Credit spent:		-98

❸ Your Softcare marketplace overview:

WE LOOK FOR:

Gardening help for:	5 CREDIT
Reading for patients for	4 CREDIT
Food delivery for	7 CREDIT
IT expert advisory for	15 CREDIT

WE OFFER:

Gym access for	FREE
Coworking space for	21 CREDIT
Healthy cooking course for	32 CREDIT
Household help for	18 CREDIT

For detailed information refer to our page www.softcare.sg

❹ Your upgraded new SOFTCARE PREMIUM card:

Updating payment information will not result in any previously declined orders.

Rachel Wong

Mrs. Rachel Wong
Director

SOFTCARE
PREMIUM
9845 1265 1027
Mr Jonathan Lee

SOFTCARE HQ Waterloo Centre Blk 261 Waterloo Street, #03-32 Waterloo Centre, Singapore

ENJOYING LIFE´S LITTLE PLEASURES

INSIGHTS

ENJOYING LIFE´S LITTLE PLEASURES

STILL LIVING WHILE DYING

- Boredom is a big problem as patients might wait passively in between planned activities or daily routines.
- Staying connected to family, friends and the world helps patients to fight isolation and depression.
- Giving people a sense of control over the manageable aspects of their death is important and empowering.
- Supporting personal hygiene routines and cleanliness is a practical and symbolic way to enhance patient dignity and comfort.
- Food is an important factor that can add quality to hospice life for everyone, but one that is often overlooked.
- Meal portions and presentation affect how patient´s feel about eating.
- Having a choice of food and a sense of freedom in eating can bring joy and pleasure to a patient.

LACK OF PERSONALISATION

- Patients need support to have their voices heard.
- Hiding the truth about imminent death creates many misunderstandings and prevents personalization of end-of-life for the patient; it doesn't allow patients to say goodbye and manage their issues properly before they die.
- A basic care principle that applies to palliative care is to understand the patient behind the symptoms.
- Nursing care tends to be planned heavily around carrying out specific tasks, which can leave nurses with little time for high touch care.
- Therapy gives alternative ways for people to express their feelings at end of life using pets, art or music as the medium.
- Patients and their loved ones need privacy & sociability at different moments during their hospice stay.
- Each patient is unique and with particular needs and different levels of readiness to face death at different moments in time.

DEATH IS A TABOO SUBJECT

- Talking about death differently helps people behave differently at the end of life.
- If death is a societal conversation, people would be equipped to coach themselves through the journey.
- People don´t want to talk about death, they don´t have the courage.
- Hospice staff gradually reveal the truth to patients or families when they think they are ready.
- It is not death itself we fear but the moments before.
- Past practices dictate current mindsets. These include not leaving a dead relative alone, arranging a funeral in the shortest time possible and providing the best, are seen as signs of respect and love from relatives to the deceased.

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- Finding viable and sustainable funding models for hospice care is a major challenge that is being met by hospices with ad hoc creative solutions.
- People, and middle class families in particular, cannot afford hospice care and are anxious about associated costs.
- Opportunities exist to streamline and balance cost with quality of care delivery in hospices.
- Many private insurances do not currently cover hospice or terminal care.
- Hospices face funding constraints, which mean that they have to prioritise care to specific groups: elderly and those with terminal chronic diseases.
- Hospices rely heavily on fundraising to fill the government subsidy gap, yet fundraising events are too predictable and are becoming less effective to meet a rising fundraising target.
- Encouraging volunteer programs can help fill a gap in resource shortages since they represent a free workforce for hospices, sometimes even being trained to attend to basic nursing tasks.
-

¨AS HEALTHCARE PROFESSIONALS WE NEED TO ENGAGE IN OUR PATIENT'S UNIQUE EXPERIENCE, TO HELP THEM COMPLETE THEIR END-OF- LIFE JOURNEY MEANINGFULLY.¨

Dr. Gilbert Fan
Head of Department,
Psychosocial Oncology,
National Cancer Centre Singapore

Patients are seated side-by-side to watch television during the day in the communal hall.

People look forward to Happy Hour in the hospice each week, it is served by a team of volunteers with drinks supplied by sponsors.

Celebrating what might be a patient's last birthday.

"I COME EVERY AFTERNOON TO DO LITTLE THINGS FOR MY HUSBAND - SHARE DINNER, PRAY TOGETHER, SING SONGS, BRUSH HIS TEETH."

Wife of a hospice in-patient

ENJOYING LIFE´S LITTLE PLEASURES

SWEET TREATS IS A HOSPICE SERVICE PROGRAM THAT OFFERS PATIENTS, LOVED ONES AND CARE GIVERS A WIDE VARIETY OF WAYS TO TAKE A MUCH NEEDED BREAK FROM THE STRESSES AND PAINS OF THE END-OF-LIFE EXPERIENCE. ASIDE FROM MANY OPTIONAL ACTIVITIES SPRINKLED THROUGHOUT THE HOSPICE DAILY SCHEDULE, SPECIAL OCCASION **SMILE PACKAGES** ALLOW PATIENTS AND LOVED ONES TO BUILD INCREDIBLE MEMORIES THROUGH EXCURSIONS THAT ARE VOLUNTEER-LED. EITHER BY INDIVIDUALS, COMMUNITIES OR SPONSOR COMPANIES. BOTH SERVICES OFFER UNIQUE WAYS TO CELEBRATE LIFE, AT THE END-OF-LIFE.

These distinct program elements help make hospice services feel less institutional and more personal, being based on a patient´s personal preferences, personality and passions. Some services can even be made available for the local community, such as the Night Owl cafe for anyone suffering insomnia and needing a welcome place to be in the unsocial hours of the night. Care Central is a safe haven. Importantly, the ability of Sweet Treats to offer around-the-clock support for patients, loved ones and citizens is in line with the highly attentive nature of palliative care.

Volunteers are the main driving force behind the delivery of these ´soft touches´ in Care Central services, but patients, loved ones and staff can also get involved. Sweet Treat activities can create ways for patients themselves to be able to give back to the community, both inside and outside the hospice. For example, by baking Thank You cookies during their Occupational Therapy session or suggesting favourite films or music to be screened or aired for the community in the Care Central auditorium. This can help to bring a sense of value and purpose in their life, right to the end of their life. It is important for patients to feel they are still living while they are dying.

The Care Central building itself has a significant role to play in creating the joyful places in which to experience these little pleasures - the provision of a butterfly garden or the ability to transform your room to private mode for individual spiritual reflection. The other concepts that promote volunteerism, such as Care Marketplace and Care Central cafe, all support the delivery and feasibility of such little pleasures.

ENJOYING LIFE´S LITTLE PLEA-

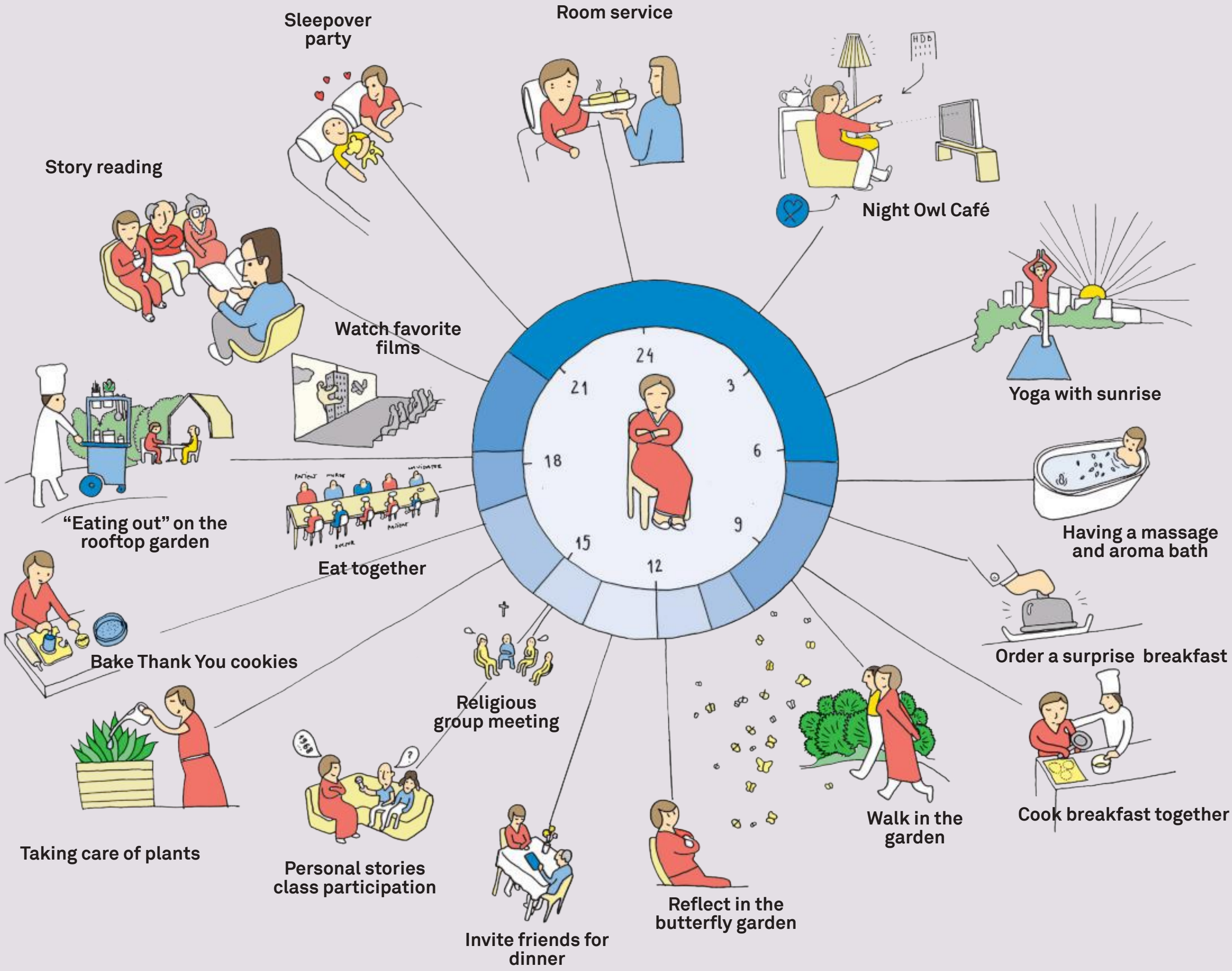
1 SWEET TREATS AROUND-THE-CLOCK

Joyful moments are scattered throughout Care Central´s programming for patients, loved ones and staff to choose from and enjoy.

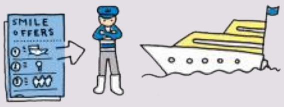
2 SMILE PACKAGES FULFILL LAST WISHES

For special occasions Care Central volunteers and Care Navigators can help to arrange memorable outings and experiences to fulfill the wishes of in-patients and their loved ones at the end-of-life. Corporate sponsors can be invited to offer financial or resource support to make a wish come true.

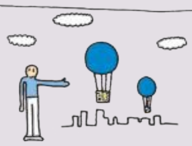
1



Staycations within Care Central network



Riding out to sea



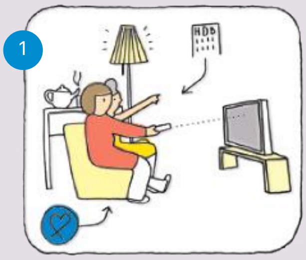
Hot air ballooning over Singapore

Offer Smile Package to care givers

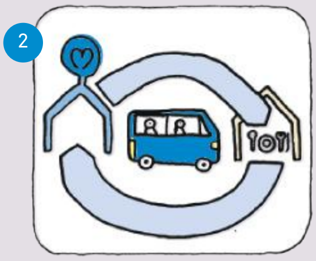
Popping home for lunch

2

SLEEPOVER
PARTY



NIGHT OWL CAFÉ

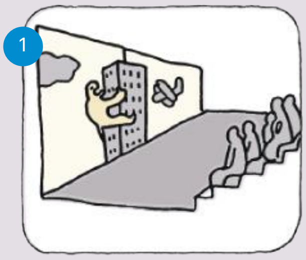


POPPING HOME FOR LUNCH

STAYCATIONS WITHIN CARE
CENTRAL NETWORK

OFFER SMILE PACKAGE TO
CARE GIVERS

STORY READING



WATCH FAVORITE FILMS

MAKING VOLUNTEERING VISIBLE AND ATTRACTIVE

raise the profile of volunteers and encourage civic participation and the notion of ´giving back´ to the community to vitalise your hospice services.

REFLECT IN THE
BUTTERFLY GARDEN

WALK IN THE
GARDEN

DESIGN WITH FAMILY IN MIND

loved ones travel the end-of-life journey with their patient and beyond into bereavement and their own end-of-life stage, they too have specific and important needs that should not be neglected or underestimated since they can enhance the experience of the patient.

OPEN SERVICES TO WIDER PUBLIC

removing stigmas, fears and barriers to addressing end-of-life issues requires reaching everyday people in their everyday lives with interesting, relevant and accessible services.

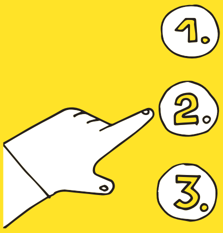
FOCUS ON THE LITTLE PLEASURES OF LIFE

create moments for people to celebrate life throughout your hospice program and space, to enjoy as much as possible the last days, weeks or months of life.

RECOGNISE THE PERSON BEHIND THE PATIENT

palliative care is holistic so patients must be taken care of beyond their disease, but with attention given also to the context of their lifestyle, their unique family set up, personal capabilities and beliefs.

EMPOWER PATIENTS WITH A SENSE OF CONTROL



end-of-life fears revolve around a sense of lost control over one´s life, so providing simple ways to regain that sense of control can help to focus and steady a person in their end-of-life journey.

INTEGRATE NATURE IN CARE

go beyond a merely ´cosmetic´ use of nature to distract and soothe the senses and find surprising and effective ways to incorporate natural elements and settings into care plans and the overall hospice experience.

MAKING IT REAL…

ENJOYING LIFE´S LITTLE PLEA-

In the future there will be many more hospice patients, with as many ways to seek pleasure. This concept is to enable the last wishes of patients to be honoured and celebrated in memorable ways. The concept provides a lense through which to view your programming and to evolve and design your current service. Formalising what may already be happening albeit in an organic way - birthday parties, outings, night owl café - and creating a structural element to bring joy into hospice life in as many ways as is possible.

POTENTIAL PILOT PROJECTS

TEN WISHES:

› Ongoingly ‘test the water’ and ask staff what ideas they would want to see if they themselves were patients in the hospice. Identify 10 small things to change, implement and experiment (e.g. bubble baths, surprise breakfasts, sunrise meditation)

SMILE PACKAGES

› Connect patient´s last wishes with people or organisations that would be willing to facilitate and make a wish come true. This could be combined with setting up a volunteer care marketplace, where Smile Packages are one item on the menu.

PLEASURE POINTS

› Consider how to create the spaces in your existing or future building plans to support and encourage these invigorating and life-affirming little moments and experiences for people. Think about the spatial and interior design elements that can influence the mood and atmosphere suitably through lighting, vistas, smells, touch, sounds.

GRATITUDE COOKIES

› Design cookie-baking as an activity into occupational therapy programs for patients or in family support group sessions. This can be seen as an extension of allied health care practice and tools, such as in music therapy where you are also given new tools or instruments with which to express your feelings and thoughts.


Thank you! Cookies
GOOD BYE
NK
U
FORGIVE ME
GOOD BYE
I AM SORRY
I
YOU

GIVING PATIENTS A VOICE


ASSISI
HOSPICE
怀 病 院
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INSIGHTS

GIVING PATIENTS A VOICE

LACK OF PERSONALISATION

- Patients need support to have their voices heard.
- Hiding the truth about imminent death creates many misunderstandings and prevents personalization of end-of-life for the patient; it doesn't allow patients to say goodbye and manage their issues properly before they die.
- A basic care principle that applies to palliative care is to understand the patient behind the symptoms.
- Nursing care tends to be planned heavily around carrying out specific tasks, which can leave nurses with little time for high touch care.
- Therapy gives alternative ways for people to express their feelings at end of life using pets, art or music as the medium.
- Patients and their loved ones need privacy & sociability at different moments during their hospice stay.
- Each patient is unique and with particular needs and different levels of readiness to face death at different moments in time.

LOVED ONES NEED ONGOING SUPPORT

- Filial piety means the younger generation feel obliged to take care of their parents.
- Busy lifestyles mean more families rely on domestic help to manage the household and care for kids and elderly.
- There is a need to balance respite care support with opportunities for active family engagement, to help manage a family´s stamina on the end of life journey.
- Emotional support is vital to offer in a timely and appropriate way, as loved ones experience a wide range of feelings from anger to relief and sadness.
- Every family is unique in the way they experience the various stages of the end of life journey and require tailored support.
- Having the time to accept an impending death helps families grieve for a shorter time.
- Advanced funeral planning of a patient can relieve the family of the stress of disagreements, discussion and decision-making around end-of-life arrangements.
- Hospice services only support families up to the moment of death and then hand over the deceased to the family, who then have to contend with and choose from a plethora of funeral service providers. They play a limited role after the deceased is handed over to a funeral director.
- Funeral Directors take the role of counsellor to console and offer emotional support to the family.
- Hospice care staff can build close relationships with patients and their families that allow them to provide continuity of care along the end-of-life journey, from hospice to wake.
- Relatives of deceased patients see volunteering as a way to give thanks and to give back to the service.

HOSPICES & FUNERAL SERVICES ARE NEGATIVELY PERCEIVED IN SOCIETY

- Sending a loved one to a hospice is seen as abandonment
- Leaving a body in a mortuary is seen as a sign of disrespect for the deceased.
- Hospice is still viewed as a ´death house´ that people want to avoid at all costs
- Hospice is seen as a depressing and strange place for professionals to work
- The actual hospice experience is usually better than people´s perceived experience.
- Faith-based hospices can seem less scary to believers of that faith.
- Funerals, like weddings, are seen as opportunities to show off your wealth, status and love for your loved one.
- Different cultures have different attitudes, perceptions and expectations and hospice care.

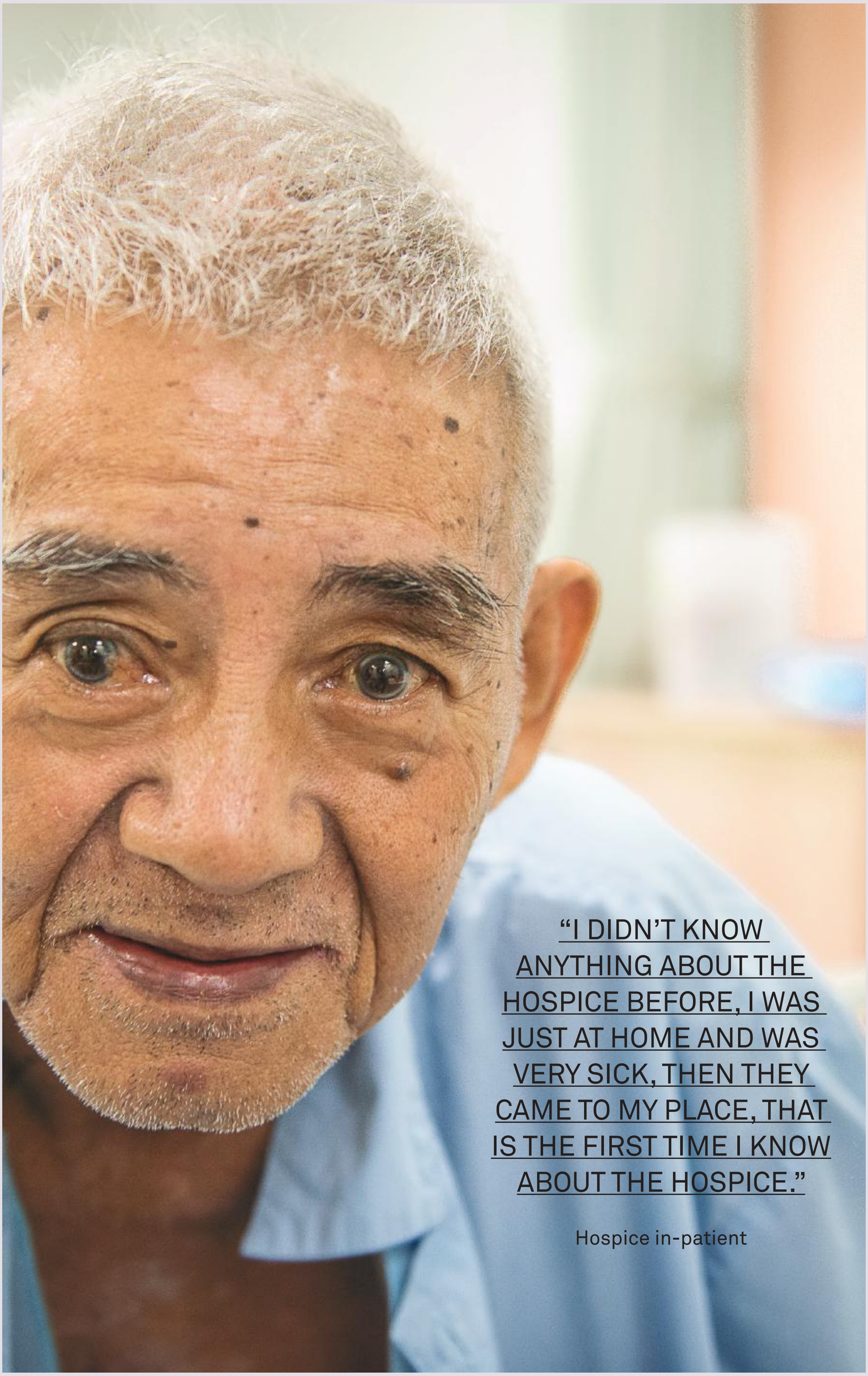
¨THE IMPORTANT THING IS THE HUMAN ABILITY TO UNDERSTAND THE NEEDS OF THE PATIENTS WHO ARE DYING.¨

Dr. Jacqueline Chin
Co-author of ´What doctors say about care of the dying´

Patients have their own wheelchairs that are labelled with their name. For comfort, they use their own cushions and blankets.

An in-patient gives his palliative care doctor a teddy bear as a small token of appreciation.

A day care noticeboard shares words of encouragement from volunteers.



“I DIDN’T KNOW ANYTHING ABOUT THE HOSPICE BEFORE, I WAS JUST AT HOME AND WAS VERY SICK, THEN THEY CAME TO MY PLACE, THAT IS THE FIRST TIME I KNOW ABOUT THE HOSPICE.”

Hospice in-patient

GIVING PATIENTS A VOICE

BESPOKE IS A CARE SERVICE THAT RECOGNISES AND RESPECTS THE FACT THAT EACH PATIENT AND THEIR FAMILY SITUATION IS UNIQUE, AND THEREFORE REQUIRE A TAILORED AND PERSONALISED CARE EXPERIENCE FROM ENTERING THE HOSPICE TO DEPARTING. IT PROVIDES TOOLS AND SERVICES TO CAPTURE A PATIENT´S PREFERENCES ABOUT THEIR ENVIRONMENT AND PRIORITIES, AS WELL AS FACILITATE THE EXPRESSING OF THEIR IDENTITY, FEELINGS AND LEGACY FOR OTHERS IN EMPOWERING WAYS.

Patients are people throughout their journey, from terminal diagnosis to passing on, each with personal preferences that determine what exactly fuels their fears, eases their anxiety, brings them comfort. Families can help to communicate needs on behalf of their loved one, but when the family does not have a proper place in the hospice service and is without a true voice themselves, this can bring further challenges in caring for patients. Bespoke captures a patient´s personal choices and responds to shape the hospice service to their needs.

Prospective in-patients can set their preferences for their personal environment, activities and services during the admission conversation with a Care Navigator who will be their point-of-contact to the service. This person can continue to adapt their choices during their stay, as their needs and priorities change.

The Patient House is an icon to represent a new home in which patients can find their comfort at the end-of-life; offering peace and privacy, options to adapt the space to socialise and feel included in the Care Central community, a place where their family can spend quality time and feel they have a place to be along the journey too.

The House has a set of flexible modes so patients and families can choose a setting most suitable for their needs, as they change over time. They are able to personalise the space with interior architecture and furniture elements as well as spiritual accessories and references. The intimate patient nook, closest to their bed, is a place designed for a patient to keep their most precious or personal items and memorabilia in an accessible and close way. A single patient house is of course the ideal setting in which a person can spend the last weeks or days of their life, but it is important to strive for this ideal in respecting fully the wishes of our dying.

It is important to note that clinical monitoring and intervention, as appropriate, can still continue in the background to the above elements. Room furniture doubles as accessory or storage to clinical tools - medications, IV drips etc. To make sure every patient is safe and has their symptoms well managed throughout their journey to the end-of-life.

After a patient passes on, the House closes and cools to become a holding room. This allows the family to have privacy and stay close to the patient in a now familiar setting, when they face shock and distress. This strategy aims to control the quality of care as a patient and family is handed from hospice to funeral home. The House has become familiar and a place that the family feels they can invite the funeral director to visit and discuss their needs and wishes, at their convenience. This helps them to make decisions without additional logistics and stress.

The Goodbye Box is an idea to ease the painful experience families face when they need to finally vacate the patient House and remove their loved ones belongings. This process of packing up is a key moment for loved ones, as they begin their bereavement journey. As well as for staff, who might face a series of these moments each day or week, leaving them emotionally drained. The Goodbye Box aims to facilitate this step of the journey with sensitivity and helping people to start the grieving and letting go process. New rituals can be developed to ease the pain of the experience. For example, taking some signature elements of the patient´s experience in their House or Care Central; families could take a living plant from the room as a memento, the design of the box itself can reflect the patient´s identity or life. The box can contain information to connect the family to Compass support services, making sure they can receive emotional and practical guidance once they leave Care Central.

GIVING PATIENTS A VOICE

1 LEARN AND RECORD PATIENT’S STORY AND PREFERENCES

Care Navigator visits their assigned patient before admission to learn about his/her life, family and relations. Recording this information helps the care team to understand the patient´s lifestyle context and prepare a personalized care experience. The patient is encouraged to express his/her preferences to customize the care environment as well as select what activities or support they might like to consider.

2 PATIENT HOUSE TAILORED TO PERSONAL TASTE

The interior design of the Patient House encourages customization. The patient can decide about elements of the decoration, equipment, furniture etc. The Care Navigator helps patients to define their preferences and prepare the new home before moving in. Volunteer teams implement the customisation.

3 DOOR KNOB CARDS

With Door Knob Cards people can express emotions and leave messages in a non-direct, tactful and personal way. Patients can choose between ready-made and customizable cards and messages. The cards have a dedicated place in each Patient House.

4 LEAVE ME ALONE FLIP-FLOP

The Leave Me Alone flip-flop is a non-verbal communication tool that allows patients to discreetly signal the wish to be undisturbed towards loved ones, care givers or fellow patients.

5 INTIMATE PATIENT NOOK DESIGNATES PRIVATE SPACE

The Nook is an interior architecture element that fits at the head-end of the patient bed and creates a personal and customisable space around the patient, whether they are in a private single room or a communal multi-bed room.

6 SERVICE TO RECORD AN OBITUARY

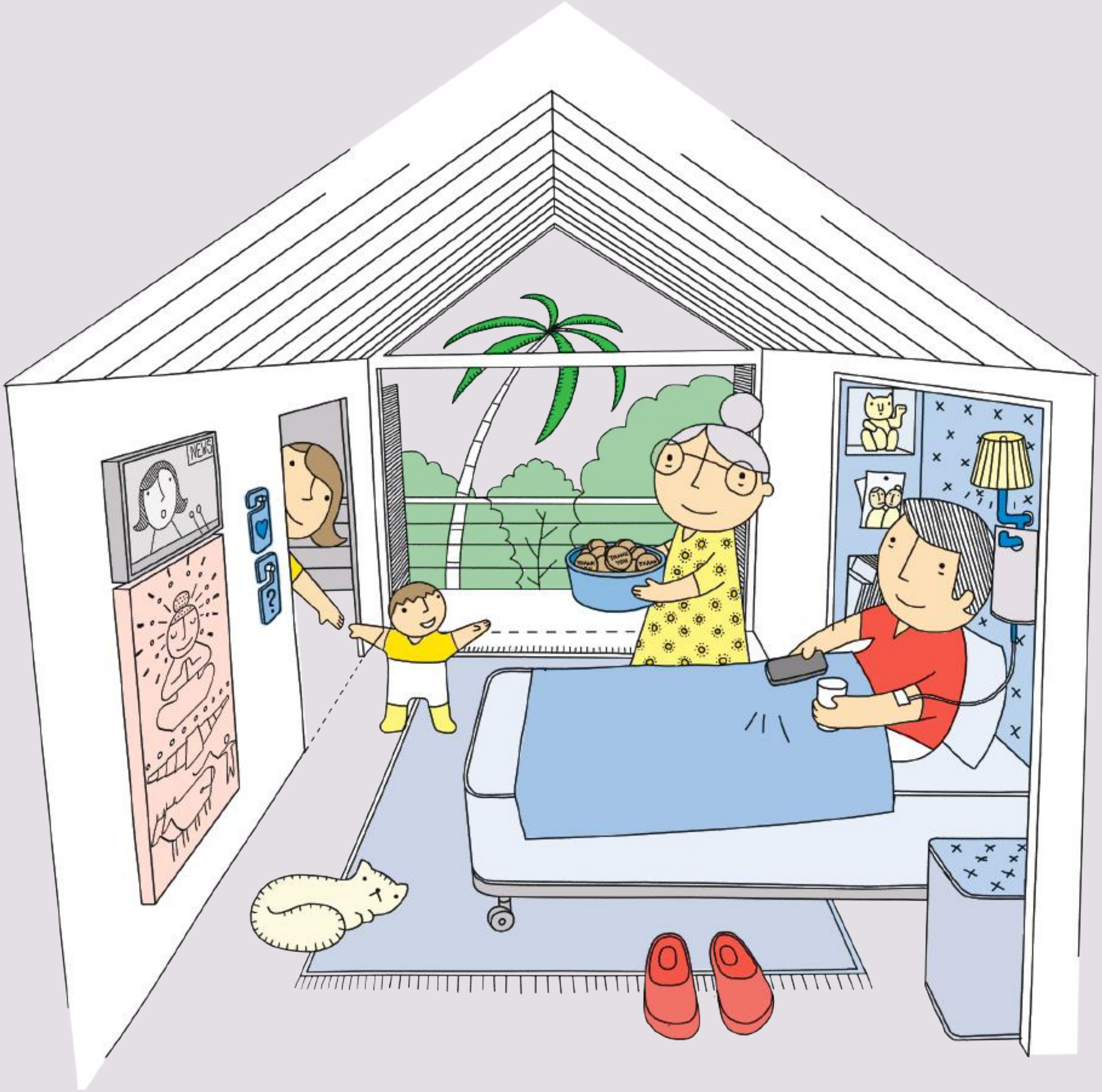
Part of the Compass Navigator service is to provide an easy-to-use tool to record an online audio obituary.

7 THANK YOU COOKIES

The Thank You Cookies are sweet gifts that can be made by patients together with therapists or volunteers, to express gratitude for the care team and loved ones in a special thanks-giving event. Cookies can be served in the Care Central café or in shops and market stalls in the neighbourhood.

8 GOODBYE BOXES TO PACK AWAY MEMORIES OF A LOVED ONE

A set of specially designed packing boxes offers a more dignifying way to pack and take away all the belongings of a loved one after he/she has passed away.

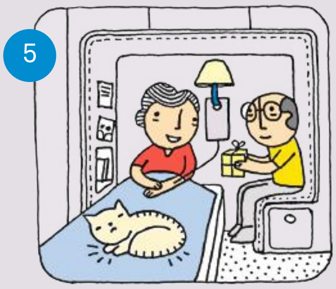


Learn and record patient’s story and preferences

Patient H ouse tailored to personal taste

Door knob cards

Leave Me Alone flip-flop



Intimate patient zone

Service to record an obituary

Thank You cookies

Packing memories

PATIENT HOUSE TAILORED
TO PERSONAL TASTE

INTIMATE PATIENT NOOK
DESIGNATES PRIVATE
SPACE

FACILITATE PERSONALISATION OF CARE

define how far you can go to personalise your service considering different levels; through furniture or products you can offer, service training you can give your staff, the environments you can create in-house as well as the tone-of-voice of all your service communications.

THANK YOU COOKIES

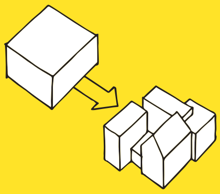
GOODBYE BOXES TO
PACK AWAY MEMORIES
OF A LOVED ONE

LEAVE ME ALONE
FLIP-FLOP

DOOR KNOB CARDS

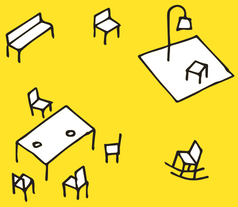
SERVICE TO RECORD AN
OBITUARY

AVOID THE INSTITUTIONAL



hospice care should clearly demarcate personal, attentive and high touch palliative care qualities, a step away from institutional care settings that tend to be anonymous and impersonal.

SPACES ADAPT TO USER



end-of-life is unpredictable and people´s condition, feelings and preferences can change spontaneously and dynamically during their hospice stay, spaces must therefore adapt to meet these ever-changing needs.

FOCUS ON THE LITTLE PLEASURES OF LIFE

create moments for people to celebrate life throughout your hospice program and space, to enjoy as much as possible the last days, weeks or months of life.

KEEP NORMALITIES OF LIFE

if you promote death as a part of everyday life then common rituals and habits can all keep their place and create a familiar and comforting sense of rhythm in people´s lives.

DIGNIFY EMOTIONAL MOMENTS IN THE JOURNEY

recognise that it is normal for people to experience emotional breakdowns and feel vulnerable, but make sure they can feel safe and secure at these times.

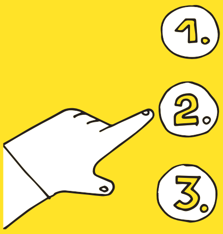
DESIGN WITH FAMILY IN MIND

loved ones travel the end-of-life journey with their patient and beyond into bereavement and their own end-of-life stage, they too have specific and important needs that should not be neglected or underestimated since they can enhance the experience of the patient.

CREATE A SAFE ENVIRONMENT TO EXPRESS FEELINGS

create a sense that any feeling is an acceptable feeling to be had inside a hospice, for patients, loved ones and staff, and that there is a considered ´place´ for this sentiment both literally and emotionally.

EMPOWER PATIENTS WITH A SENSE OF CONTROL



end-of-life fears revolve around a sense of lost control over one´s life, so providing simple ways to regain that sense of control can help to focus and steady a person in their end-of-life journey.

MAKING IT REAL…

GIVING PATIENTS A VOICE

Single patient rooms are an ideal solution that offers patients the choice of privacy and intimacy at the end-of-life. The main limitation or bottleneck to offering this is an overall lack of space and the need to serve high demand on the same footprint of land. But the guiding design principle should be that anyone in hospice care deserves a basic level of privacy and intimacy, for example to facilitate conversation with family and care givers, no matter if this relates to a single or multi-bed room.

Personalisation is recognised as a vital ingredient in palliative care, each patient and family being unique. Try to think about how far you would like to and are able to take this principle within your service and practices; are there ways to trigger and make it easier for your staff to tailor their service delivery? Simple tools that make it easier to remember to to act to personalise their stay and help teams to ´go the extra mile´ in caring for a patient or family.

POTENTIAL PILOT PROJECTS

PATIENT NOOK

> Develop a standalone interior design element that creates a ´private zone´ around the patient bed for both patient, care giver and family; creating a cosy, intimate and personalisable space at the head end of the typical patient bed introduces a new visual icon for personalised care. This can be applied to a range of palliative care settings including hospital department, hospice, nursing home and become a signifier of any palliative care area whether in a single or multi-bed room. It would bring a non-institutional flavour to the room, creating a unique identity and creating more of a ´place´ than just a room.

DOOR KNOB CARDS

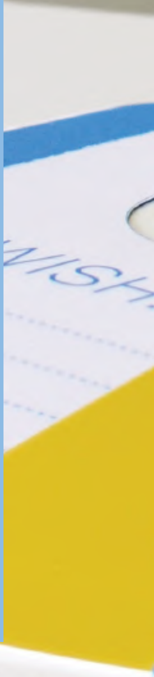
> These can be relatively easier ideas to implement in the short term since they are low technology, analogue paper-based solutions that can enhance an existing service in an existing space. Find out from patients, care givers, volunteers and family what messages can be appropriate and fitting to the culture and atmosphere of the hospice. Allow for the service to evolve over time, an open service that can be adapted by people over time.

PACKING UP MEMORY BOXES

> This is a step in the process of death and dying that always happens, that has to happen, but that has so far not been fully considered. Experiment to find emotionally and culturally sensitive ways to implement this idea working with care teams to prototype solutions. It is an idea that can be combined with patient art therapy programs, allowing people to create personalised memory boxes for themselves of loved ones.

PATIENT HOUSE

> Explore the features of this care setting that is more of a home than a room. Try out different modes of use - shared, flexible, openable, adaptable to create a family setting, a specialist clinical suite for isolation or infection control, or a high end luxury suite.



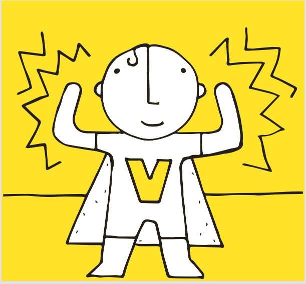

COME IN!
JOIN ME!
☐ Gym
☐ Music
☐ Cooking
☐ Coffee
☐ Movie
☐ Table game
☐ Dinner
☐ Tea
☐ Walk
☐ Shop
OR?
WHERE?
WHEN?
WHO?
EAVE
E ALON

24 EXPERIENCE DESIGN PRINCIPLES

1.
CREATE A COHERENT
CARE BRAND

2.
GUIDE PEOPLE
THROUGHOUT THEIR CARE
JOURNEY

3.
INTRODUCE EARLIER
TOUCHPOINTS TO CARE
ECOSYSTEM

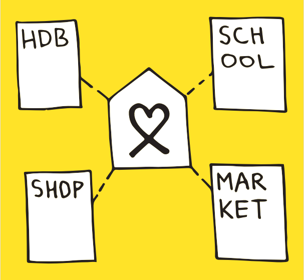


4.
MAKE VOLUNTEERING
VISIBLE AND ATTRACTIVE

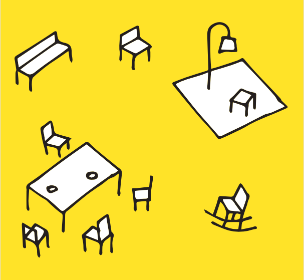
9.
EMPOWER PATIENTS WITH
A SENSE OF CONTROL

10.
RECOGNISE THE PERSON
BEHIND THE PATIENT

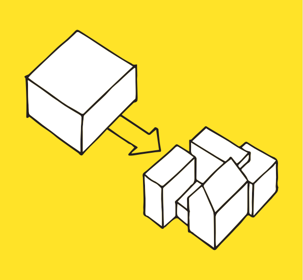
11.
DON'T SEPARATE THE SICK
FROM THE HEALTHY



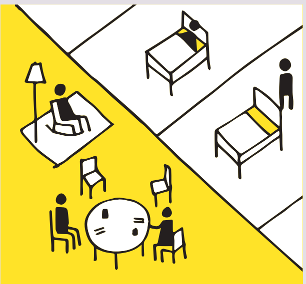
12.
BUILD NEIGHBOURHOOD
CARE COMMUNITIES



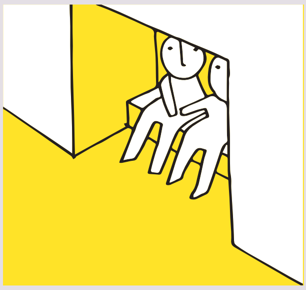
17.
SPACES
ADAPT TO USER



18.
AVOID THE
INSTITUTIONAL



19.
MAKE
SOCIALISING EASY



20.
SUPPORT EFFORTLESS
WITHDRAWAL TO PRIVACY

5.
DIGNIFY EMOTIONAL MOMENTS IN THE JOURNEY

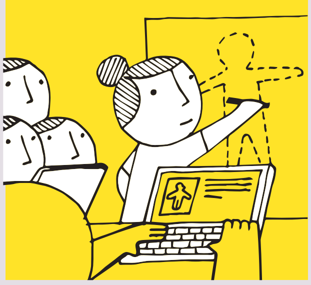
6.
KEEP NORMALITIES OF LIFE

7.
FACILITATE PERSONALIZATION OF CARE (LANGUAGE, FOOD, ETC)

8.
DIRECT COMMUNICATION CHANNELS AMONGST STAKEHOLDERS)

13.
PROVIDE ACCESSIBLE CARE

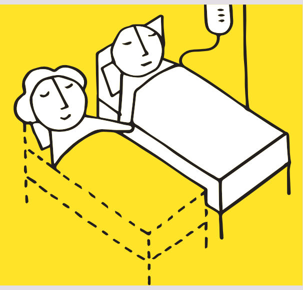
14.
FOCUS ON THE LITTLE PLEASURES OF LIFE



15.
FOSTER A CULTURE OF LEARNING IN CARE TEAMS

16.
INTIMATE, HUMAN-SCALE SERVICE

21.
OPEN SERVICES TO WIDER PUBLIC



22.
DESIGN WITH FAMILY IN MIND

23.
INTEGRATE NATURE IN CARE

24.
CREATE A SAFE ENVIRONMENT TO EXPRESS FEELINGS

CONCLUSION

Having completed this design exploration and identified what could improve in-patient hospice care experiences, it is clear that the concepts and design principles have broader relevance beyond Singapore. Many issues surrounding end-of-life are universal. It is hard to confront mortality. Navigating healthcare systems that are not well designed to deal with the end of life makes the final exit a hard one.

The results of this project challenge conventional thinking on what is possible, feasible and desirable in today's hospice care. Design has a role to play in advocating for change in our healthcare systems and experiences; we have used design thinking and an insights-based approach to re-imagine the future hospice – where the walls surrounding death and dying are broken and end-of-life care permeates the community.

We envision a world of the hospitable hospice - where people welcome and accept hospice care as a service that truly matters to them; patients are empowered to voice their needs and wishes; families have the tools and support to feel confident taking decisions on the end-of-life choices they face; and hospice spaces are directed and designed to maintain and celebrate the best of life until the end.

To realize this vision, there are key hurdles to be conquered. Patients would have to realise that they can still exercise their personal choices even when faced with terminal illness. Families would need to overcome their fears of discussing end-of-life choices. The hospice care community would need to look beyond their day-to-day challenges and step outside their sphere of influence to explore partnerships with other providers, sectors and organizations. Policy makers have the challenge of designing an eco-system of end-of-life care that includes death care providers, balancing it sensitively with the delicate and detailed nuances of palliative care delivery.
Given such challenges, it would be too easy to dismiss this ideal vision. However it is important to realise that it is not necessary to work on all seven proposed concepts at once. Even taking small steps can eventually lead to bigger change. This is especially true in Singapore, with its scale and drive for healthcare innovation through design: both top-down from the government and bottom-up from the community.

As a design team, we have been inspired by the stories we have heard, the places we have visited and the people we have spoken to. The journey has impacted us on a personal and professional level. Having better understood the fears of death and mortality; we see our work in a new light. Several team members were moved to start their own end-of-life conversations with their loved ones. We welcome feedback and a dialogue with other countries, cultures or organisations wanting to improve care for the dying.

We hope that our work can create more conversations about death and dying – so much so that society can talk about death in the same way we can speak about marriage and birth - free from stigma, fear and taboo. This would be an invaluable legacy for generations to come.

For sure, new hospices and services will be built in the future to cope with the increased demand from ageing populations. This increased need can be turned to an advantage as the momentum is set for more programmes to test new concepts, and fine tune solutions to raise the standard of care we can give to our dying citizens and their families.

We hope you will welcome the Hospitable Hospice into your daily lives.

IMPACT

´This is a most remarkable, thought-provoking and helpful publication. I would consider ´Hospitable Hospice´´to be essential reading material for anyone leading a hospice into the future.´

David Praill, CEO Help the Hospices UK

IMPLEMENTED SOLUTIONS

The Hospitable Hospice design strategy has inspired and informed policymakers, public and private service providers and innovation teams in Singapore and beyond. And here are examples of two distinct concepts that have since been implemented in Singapore, with others currently in development:

Care Central: A conceptual building model designed to be flexibly implemented by different types of hospice organisations and for different scales of building and service. All three hospice project partners used the Hospitable Hospice design guidelines to articulate their needs to their architects, and to develop their own unique service strategies and solutions for implementation in each of three new hospice facilities in Singapore. (St Joseph's Nursing Home & Hospice, Dover Park Hospice and Assisi Hospice.)

Bite-Size Future: An end-of-life conversation toolkit that rewrites this difficult conversation for families. It not only contains trigger questions to cover important topics for discussion, but creates the atmosphere and opportunity to hold such a conversation – inviting families to an afternoon tea, complete with biscuits and the gentle guidance of a trained facilitator from the nursing home or hospice. St Joseph's Home care team co-designed the solution and is currently implementing it in their new facility.

MISSION-BASED SERVICE DESIGN

Our experience showed that Hospitable Hospice marked a new typology of service design project, where design contributes to tackling complex societal challenges and transforming our care experiences on multiple levels: from policy to services, infrastructure to technology tools, service toolkits and accompanying skills training.

It illustrates well what we see as a new field of mission-based service design for the health and care domain, one that can deliver systemic-impact outcomes and where the service designer acts as an advocate and activist for human-centred innovation. In mission-based service design such as this, engaging the ecosystem is an essential element for success.

The project also demonstrated the responsibility we believe that service designers specialised in health and care have to engage and empower the wider ecosystem in the practice of innovation.

It is important to involve the relevant stakeholders to understand firsthand, in-depth and in-context their key issues and needs, and to co-design and co-implement with them the most meaningful, viable and transformative ideas that can sustainably improve the way we care for one another.


Quality of Life
Concerns & Fears
Wishes
Planning the Future
End of Life
Who do you want with you when you die?


Memorybox
Memorybox


Apex Harmony Lodge
Strategic Planning Toolkit
OUR MISSION / VISION
Inter-generational engagement

THE SOCIETAL BACKDROP

FEAR OF DEATH AND DYING PERSISTS

Public perceptions and attitudes to death and dying have been slowly shifting since organisations such as the Lien Foundation have started measuring opinion and advocating for change through campaigns such as the Life Before Death initiative. However, perceptions are typically slow to change, even more so around a topic such as death and dying, with its very specific and long-standing taboos and beliefs practically hard-wired into generations of Singaporeans.

Singapore´s multi-faith and multi-cultural profile creates for an even more complex web of perceptions around death and dying. Different communities and religions practice their own distinct rituals to deal with death (access the link in Appendix for a visual overview of funeral rituals). For example, ´death houses´ existed in Singapore in the 1960s and were known as a place for chinese communities. They offered comfort care, albeit not by professional care givers but charity workers or volunteers. Older generations still remember this and harbour old resistance and fear of such a ´death house´, seeing today´s hospices as their equivalent. It is bad luck to die there and to visit at certain times of the year. Although younger generations may not know so much about it, they still have a general fear and resistance to thinking about death. This is true amongst different religious and secular communities.

Such fears and superstitions create ignorance and avoidance of the issues around end-of-life. This not only affects individual lives and family lives, but also the negative perception of hospices. This influences how professionals might consider working there and citizens are turned off the idea of volunteering there.

REFRAMING AGEING IN A GREYING SOCIETY

In 2030 20% of the population will be over 65 years old in Singapore. Several public, private and partnership initiatives in the health sector, as well as grassroots community-driven projects are working hard to define new strategies, infrastructure and services to cope with this challenge. The Ministry of Health has created an Ageing Planning office and plans are being announced about new integrated care settings that place care services into the community to support young working families and ageing citizens.

The social welfare of citizens is becoming even higher priority. There is a sense of responsibility to look after those ageing citizens who have been instrumental in making Singapore the country it is today; they deserve to be cared for by the country they helped to build and to benefit from their contribution. Shifting focus from caring for individuals to caring for families, from caring for the workforce to also caring for the elderly, comes with a growing acknowledgement that neglect of longer term care and eventually end-of-life care can have negative social impact.

Worldwide the concept of ´active ageing´ redefines the experience of ageing; according to the WHO definition, this is ´the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.´ Implicit in this is also the idea of ageing-in-place that is also key strategy element for Singapore; of being able to stay in your own home and neighbourhood as you age and to continue contributing to and benefitting from this social inclusion. Such ideas lead to the creation of new models of care that are better integrated into local communities, yet also connected to and supported by the wider healthcare service network.

Within this reframing of ageing, there is also a shift in attitudes and expectations; having a sense of self-esteem and independence as you age is as important as staying mobile and physically well. It is this healthy acceptance of ageing as a natural but also positive new life stage that creates the opportunity for the end-of-life to become as natural a life stage into which we can hope to progress with a sense of accomplishment, rather than of dread and fear.

THERAPY STILL HOLDS TABOO

Singapore is a ′vocally conservative′ society, especially on sensitive, personal or contentious topics. People do not easily open up about their problems, even amongst family members let alone to an ′apparent stranger′. Therapy is a taboo subject; accepting help means you are admitting you are somehow a ′failure′ in society.

This is true for both patients, loved ones as well as professional care givers. Despite having third party therapy services available to them, hospice staff are reluctant to reach for this help and taking sabbaticals or leaving the profession altogether are the preferred ways to recover from stress.

This general sensitivity means that when patients or loved ones do manage to open up and share their emotions and feelings with a professional, they do not want to have to be passed to another and have to go through the whole painful process over again. Having a single, experienced and trusted point of contact and support throughout the care journey becomes extremely important.

NEXT GENERATIONS ARE INCREASINGLY TECHNOLOGY-SAVVY

The future generation of care givers will be from the so-called Generation Y segment who are more technology savvy and often called the ′Digital Natives′. This is the generation who grew up with social media and for whom online, networked service and experiences are part of everyday life to an extent that they cannot imagine to live, work or even die without them.

This phenomenon is reflected also in generations of professional care givers, with younger nurses and doctors more familiar with and expecting to use technology tools for communication, learning and social networking. While the older generation of doctors and nurses might find new technology tools seemingly cumbersome and overwhelming to integrate into their tool kits and practices. This is true within the healthcare sector and particularly so in the hospice sector where professionals are generally less technology savvy compared to their counterparts in the acute care sector.

From its origins as a grassroots movement, the hospice end-of-life care sectors have less digital infrastructure in place. Only now they are being brought in line with and up to date within the latest national healthcare IT frameworks and platforms.

As more and more consumer as well as healthcare services will utilise the possibilities of new technologies to track, capture, analyse and distribute our data the ability and attitude to technology use will be a key differentiator amongst the future patients, loved ones and professional care givers of the hospice service.

STRAINING SOCIAL FABRIC

Family structures are changing in Singapore, very much in line with similar trends in other parts of the world; away from the traditional nuclear family model and increasingly disparate, with children moving to study, live and work away from their parents and helpers living-in with families to care for both young children and elders. The pressure on the main breadwinners to keep working and earning in order to maintain a desirable lifestyle and create better opportunities for the family, keeps working Singaporeans out of the home and with a feeling that they cannot afford to give up work to care for their elder or ill loved ones. There is increasing reliance therefore on foreign domestic workers as essential components of contemporary Singapore family life.

A couple of other societal changes that are affecting family cohesion and structure include an increase in divorce rates detected amongst the Singapore Malay community. And, as with other East Asian countries, Singapore is suffering low fertility rates that the government is trying to boost with incentives, until citizens are effectively able to replace themselves.

On a societal level, experts mentioned that although they do see positive signs of a return to a community-sensibility, that in general there are still low levels of civic responsibility. People do not feel compelled to invest in their direct local neighbourhood, seeing their neighbourhood as a temporary location until they can afford to upgrade their homes and housing and move to other areas of the city or even to go overseas. However, Singapore is pushing ahead with new community-integration projects and strategies that will bring into fruition the idea of ′urban kampongs′. And with this, the promise to reinforce the social fabric and create an impetus for community-led change and innovation.

RELEVANT TRENDS

DRIVERS RESHAPING THE END-OF-LIFE LANDSCAPE

A set of trends, considered relevant to the end-of-life care landscape in general and to hospice care in particular, were gathered through secondary desk research. They were validated and enriched through interviews with domain experts in Singapore. They represent some of the key influencing forces that look likely to reshape the end-of-life landscape and hospice care services over the next 5 to 10 years. Striving to future-proof the design vision for tomorrow´s hospice, the collective implications of these different trends were taken into consideration during the creative process.

AGING POPULATION

According to WHO, population ageing is unprecedented, without parallel in human history.

RISE OF CHRONIC DISEASES

The demography of mortality is shifting from acute to chronic diseases: cancer, stroke, COPD.

DISINTEGRATION OF NUCLEAR FAMILY

Families are now living in separate households, and even in separate countries.

GENERATION Y FUTURE CAREGIVERS

Gen Y are more educated than older generations, more demanding of services, and more technology-savvy and time poor.

AGING OF BABY BOOMERS WILL BE SIGNIFICANT

As waves of baby boomers retire, their health care needs will put significant strain on the economy.

PATIENTS AS ULTIMATE CUSTOMERS

Upper and middle class patients are going “shopping” for care to enhance their basic insurance covered options.

RISING HEALTHCARE COSTS

With more long term care patients, investments in new technologies, inefficiencies in care delivery and profit-oriented providers - care costs are rising.

TAILOR MADE INSURANCE FOR ELDERLY

Government insurance schemes are extending cover to include also older elderly. While private payers customise packages for aging boomers, and influence end-of-life care decisions.

DESIGNING DEATH

A growing preference for personalised and themed funerals, as well as pre-planned, pre-paid and online services that are conveniently packaged by funeral homes.

EXTENDING PALLIATIVE CARE BEYOND CANCER

Chronic disease management strategies incorporate palliative care, as people need to live longer with debilitating conditions.

HOLISTIC CARE DELIVERY

Multi-disciplinary extended and integrated care teams are better equipped to handle complex condition, treating body, mind and soul.

ADVANCE CARE PLANNING MADE AVAILABLE

ACP is promoted by governments but people do not understand the tools and are still slow to adopt them.

FROM IN-PATIENT CARE TO AMBULATORY CARE

Primary and long term care is being pushed into the community: hospices, rehabilitation centres, nursing homes and homes.

REDEFINING HOSPICE CRITERIA

Removing the 6-month life expectancy limit for patients allows services to extend hospice care to complement curative treatments.

BUILDING HEALTH CITIES

Bundled healthcare services are integrated in one location, serving the young, working families, retirees and the elderly with preventative, acute, long-term step down and palliative care.

SMART IT SYSTEMS

Connected products on 24/7 generate continuous data about our lives. Analysis software can make sense of Big Data. Cloud computing can personalise and globalise it.

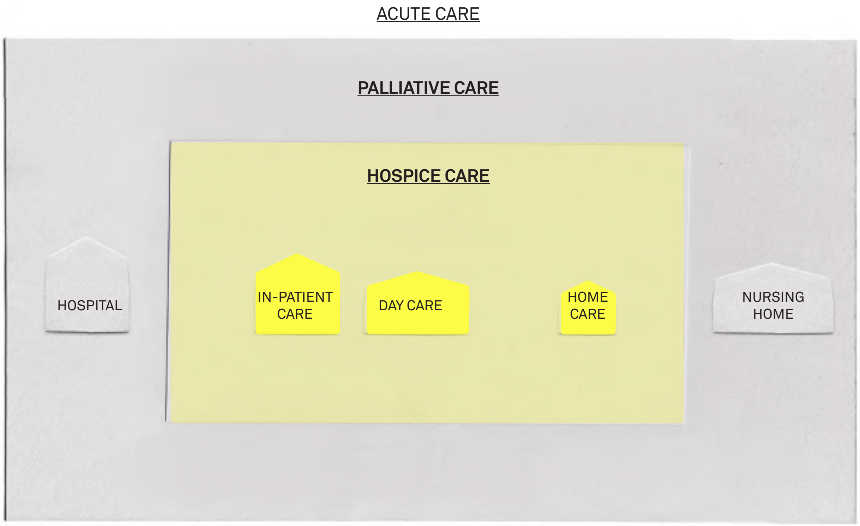
EMERGING INTERNATIONAL MARKETS AND PATIENTS

N11 is the emerging economic force, amongst which is Indonesia. International medical tourists are increasing, including those seeking cancer-related care services.

ECO-FRIENDLY FUNERALS

Lack of space for traditional funerals and a changing mindset towards sustainable thinking is driving the growth in the eco-friendly funeral.

HOSPICE & HEALTH CARE BACKDROP



PALLIATIVE CARE IS... both a philosophy and a system of care delivery that offers an holistic approach to caring for patients and their loved ones at life´s end. The main goals are: to prevent and relieve pain & suffering, to optimise functioning and support quality of life and to support decision-making at the end-of-life. To achieve this requires assessing and addressing the physical, emotional, psycho-social and spiritual needs of each patient and their loved ones.

HOSPICE CARE IS... an application of palliative care that is aimed at a specific population of terminally ill patients whose life expectancy is less than 3 or 6 months, depending on the country and policy. The main goal is to provide compassionate, comprehensive,person-centered care to terminal patients and their families at home or in a home-like setting.

A FRAGMENTED END-OF-LIFE CARE LANDSCAPE

Governments serve citizens, healthcare systems serve patients and funeral homes serve clients. In reality these are one and the same people, engaging with touch points in different areas of services but along the same experience flow. The healthcare system is filled with holes when it comes to palliative care service delivery. The handovers between organisations are not always effectively coordinated, thereby impacting the smoothness and consistency of the journey from a people perspective. In general the gaps are larger and harder to bridge between organisations (e.g. between hospital to hospice) than those between services within the same organisation (e.g. between home to hospice or day care).

The transition between the public hospices and funeral homes is also not easy to streamline. Hospice facilities do not offer a space where funeral directors can meet families. Understandably there are challenges as a hospices hand over to a funeral provider, the hospice staff cannot expect or manage the quality of care in this handover point. This is problematic.

Another discontinuity in experience flow appears during the referral process from hospital to hospice care. Due to administrative processes to safeguard costs and care quality, coupled with the communication gaps that naturally exist between organisations, patients and their families can feel as they are left without adequate support in decision-making.

Today, individual hospices find ways to maintain continuity of care despite these kind of fragmentations in the system. Care teams have to resort to hand-crafted one-off solutions to smooth the journey, they have to go the extra mile to smooth the patient and family experience for the patient. This can be very challenging to sustain on a day-to-day basis.

A CASE FOR COMMUNITY-INTEGRATION STRATEGIES

Land scarcity in Singapore is a specific factor that drives the appeal of community integration planning strategies, particularly in public service design. In healthcare this approach is attractive also for other reasons as the sheer volume of patients increases, without a parallel growth in provider resources. More people suffering chronic diseases and requiring ongoing care, more informed and demanding patients and an increasingly ageing society. All these factors make home-based, community-based and self-care very appealing from a cost-efficiency standpoint. Networked and wearable healthcare technologies can now support remote monitoring and management of diseases and health conditions. However, equipping citizens, patients, families to cope with this new landscape of healthcare solutions is another challenge. Instilling communities with the right skills, mind set and providing them adequate support and reassurance can create a sustainable move towards integrated healthcare.

SYSTEM LIMITATIONS ARE DISRUPTING CARE CONTINUITY

There are some restrictions in the protocols and processes around hospice care delivery that make continuity of care, particularly from hospital-to-hospice, a real challenge for and especially for doctors and social workers who tend to be the key contacts for a patient and their family. An example of this is he fact that officially, it is not always possible for doctors or social workers to accompany their patient into a hospice. Patients and families gain a sense of reassurance if their referring care givers can somehow be part of their transfer to a new care setting, having gained trust in them while at hospital and also in their decision that referral to hospice in the first place is in fact the best option for them. Again, some professionals take the extra effort and time to provide this continuity in certain cases where they can manage it, perhaps know the hospice team well or feel a particular patient and family need this help especially. This scenario should be the norm, whereas right now it is the exception.

There is still a poor understanding of palliative care amongst referring clinicians. This impacts the effective referral of patients into hospice care - often referral happens too late and as a last resort - making optimal palliative care for a patient a real challenge for hospice teams. Time-consuming administrative paperwork that needs to be completed before a transfer is possible is a bottleneck when there is such a shortage of hospice staff. It can hold up the process of referral from hospital but also transfer of a patient between home, day, and in-patient hospice services. These factors, together with a shortage of available in-patient hospice beds create obstacles for patients to enter hospice and receive palliative care as soon as they need it.

Despite these challenges, hospices try their best to operate flexibly between separate services (home care, in patient care, day care) to cater to the changing needs of each patient. This is possible since many of them do offer distinct ´bundles´ of palliative care services; some combine in-patient care with home care, others add day care and ambulatory care and some nursing homes offer basic palliative care. When a hospice can manage its own transfer processes it has a better chance of creating a smoother and more efficient patient journey.

TRENDS IN PALLIATIVE CARE

Both the World Health Organisation and Singapore´s National Strategy for Palliative Care promote the use of palliative care earlier in the care pathway of a potentially terminal patient. ´Slow care´ is a term that is also being used internationally to define the special qualities of palliative care giving, and broaden its application alongside other types of preventative, curative or rehabilitative treatment. The emphasis is on the highly attentive and high touch nature of care, and its ability to complement other types of care and ease the journey for patients. Such strategies place an even greater importance on multidisciplinary collaboration in healthcare teams, as they deliver several types of care at different stages of the patient journey.

Singapore now has a set of strategic recommendations related to palliative care that can help to set the scene for changes needed in the hospice care area. Many of these recommendations resonate directly with the insights gathered in this study, particularly in relation to staff experience and care delivery. The proposed concepts from this study can therefore be used to enrich the planning of next steps and potential pilot projects. There could be moves also to integrate in-patient hospices into acute care hospital settings, where over the years investment in healthcare has been focused and as a result these hospitals are strongly established preventative and curative facilities. However, it will be important as hospice care blends into the fabric of these building, that there remains a clear distinction in the care philosophy and approach required for palliative care. Hospices that are in hospitals should feel special, more intimate, less clinical and institutional, more like home. This should be expressed through the architecture, signage and communication, uniforms, service quality and programming. Consider hospice as an annex to a hospital, like stepping into a slightly different world away from curative and towards palliative care.

Home hospice care will certainly be a core element of any future hospice service, it will not be possible or necessary to care for the number of people requiring some level of palliative care in the future, inside in-patient hospices. Palliative care can therefore be distributed across types of hospice care as well as into long term care settings such as nursing homes and care homes.

STAFF SHORTAGES OVERSTRETCH THE SERVICE

There continues to be a heavy reliance on foreign nurses in general in Singapore healthcare services, this is also the case in hospice care. Nurses come from places like Myanmar, India and the Philippines, with qualifications that are not always accepted in Singapore, so they need to retrain locally on-the-job alongside local qualified nurses. The status of nurses is rising in Singapore, better pay and conditions attract young graduate nurses overseas. A key resource challenge for hospices lies in attracting, recruiting and retaining nurses, social workers and clinicians trained in and willing to work in palliative care within a hospice setting. Government grants are available to attract foreign professionals as well as overseas Singaporeans back to work in Singapore healthcare.

Impacting this issue is the fact that hospices are seen as slower, less demanding and perhaps less exciting areas to work in compared to high-performance intensive and acute care services in hospitals that are geared to curative life-saving care. Hospice might rather be a choice at the end of a nursing career for example when acute care areas become too demanding to work in. Less likely that a graduate nurse would choose to begin his/her professional experience in hospice. Efforts are being made to expose trainees to hospice settings, creating role-models and encouraging specialisation in this field.

STAFF WELLBEING DRIVES PATIENT EXPERIENCE

Staff who have worked in acute care settings and move into hospice-based work, welcome the slower pace. Stress does not come from adrenalin-charged moments in the same way, but from exposure to the stresses associated with end-of-life. This is something team members learn to cope with in various ways, formally and informally.

Staff spirit and wellbeing has been recognised in other studies as having an impact on the patient and family experience of care in hospices. This puts staff morale as a priority, however the same taboos and preconceptions in society of course are reflected in this professional community and require similar breaking down of barriers and taboos to address wellness amongst the palliative care workforce.

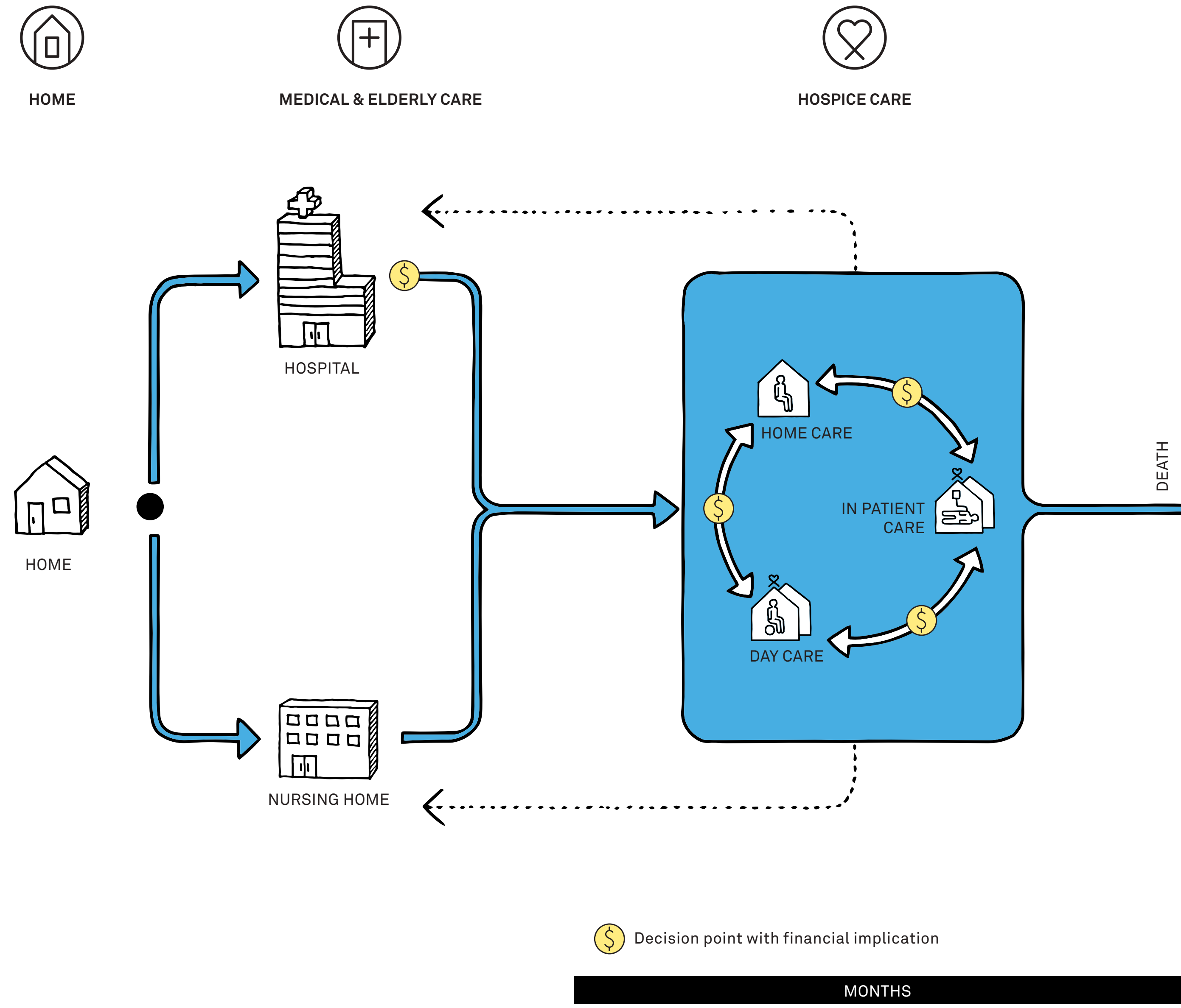
HARNESSING THE POWER OF COMMUNITY

Hospice began in Singapore as a grassroots movement that wanted to take care of the dying. The government was debating at the time whether or not to legalize hospices, but the community believed that such places were necessary and began to mobilise themselves to establish the sector bottom-up.

Matters of life and death are at the heart of every community. Strong communities can support the work of hospices or nursing homes, when people start to look out for one another in the community. However, in such a diverse, multi-cultural society as Singapore experts say you need a good deal of energy to create a common sense of community. But communities can drive and help to sustain fundamental changes in end-of-life care.

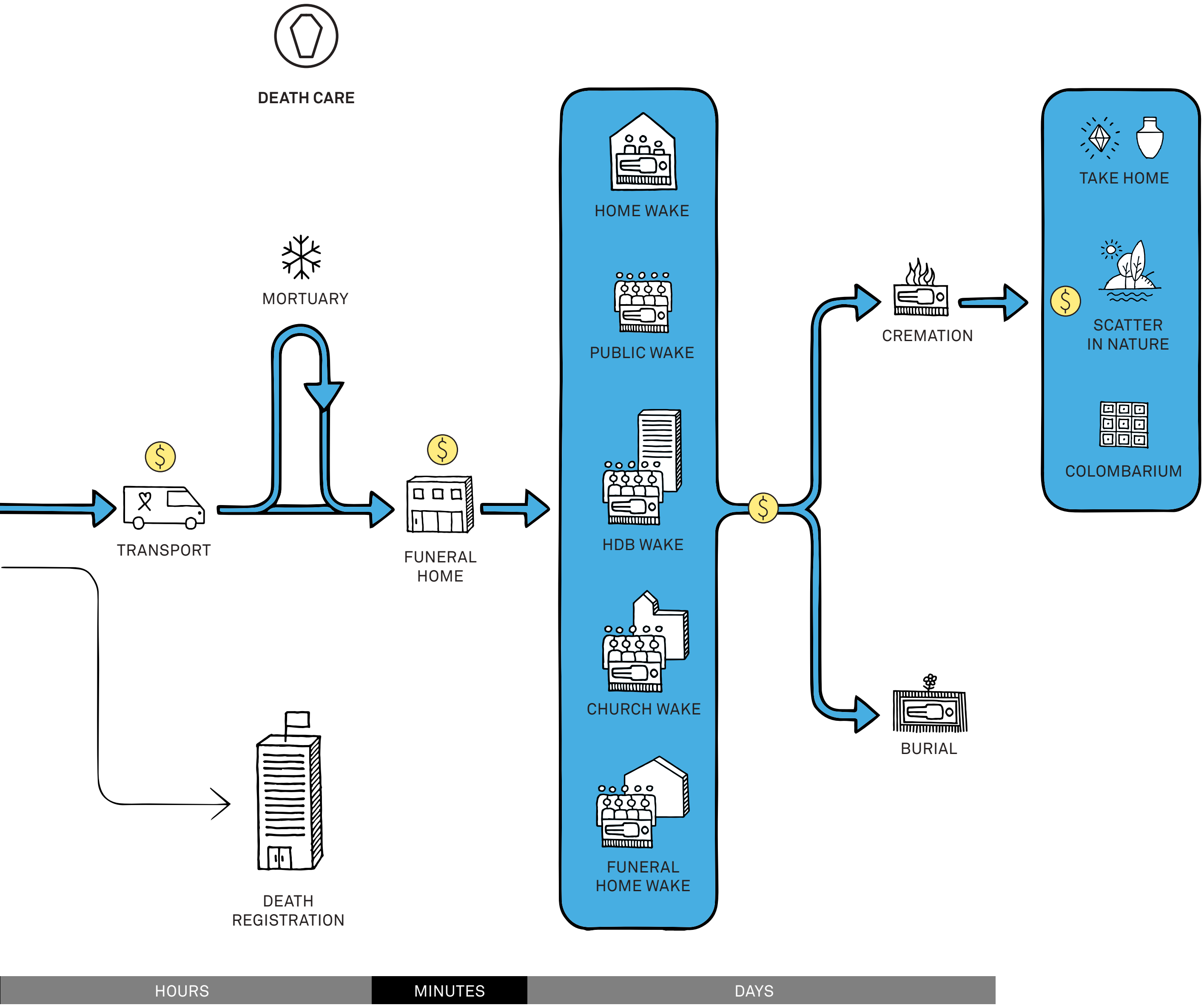
THE CURRENT HOSPICE CARE JOURNEY

TYPICAL CARE PATHWAYS THROUGH HOSPICE AND INTO DEATH CARE SERVICES



Synthesising the insights gathered through the various layers of design research (online, expert interviews, fieldwork visits) an end-of-life care journey map was created to visualise the main pathways and flows that currently exist in Singapore. It shows how people flow through and between different settings and services, from home to hospital and hospice, funeral home to crematorium or columbarium. And sets the scene for identifying key bottlenecks and opportunities for improving the experience.

Visualising this overall journey sets the scene for the project team to identify major bottlenecks, gaps, fissures and opportunities for improving the end-of-life experience for citizens, patients, loved ones, care teams and service providers. And understanding how impacting the hospice care experience relates to the overall journey that patients and loved ones pass along at the end-of-life.



INTERNATIONAL BEST PRACTICES

BENCHMARKING RELEVANT CARE SERVICES, SPACES & CAMPAIGNS

Online design research was carried out to gather examples of relevant design references: products, services, communication campaigns and architectural space concepts. Drawing from healthcare, but also other sectors such as retail, travel and hospitality in order to cross-fertilise thinking.

The purpose of this secondary design research was to build a set of design references for experiential qualities related to: aesthetics, behaviours, tone of voice. This served as an important visual inspiration tool that can be used to assess the right qualities for a hospice solution and develop specific concepts further; should a hospice service be as ´friendly´as this travel service? What makes this campaign have a ´respectful´ tone of voice and how can we use similar qualities for hospice services? What spatial qualities are working to create an atmosphere of ´calm´ in this spa setting?

A separate Evernote database was created for ongoing reference, with selected examples incorporated into a printed A3 visual Inspirational Book that was used in the design workshop and concept development phase of the project.

Here below are selected examples for reference. Please see Appendix for further details.

Maggie's Centres (UK / Hong Kong / Spain)

´Maggie's is about empowering people to live with, through and beyond cancer by bringing together professional help, communities of support and building design to create exceptional centres for cancer care.´

This is a strong example of a service that considers patients first and foremost as people, going along a cancer journey. The centres promote an holistic approach to care, reflected in the non-institutional design of its spaces, communications and service. The kitchen table is a core feature in each Centre, an icon of warmth and approachability. Centres each have their own identity and are located as annexes beside a hospital.

http://www.maggiescentres.org/

Dementia Village (Netherlands)

´Hogewey´s 152 residents – never referred to as “patients” – have all been classified by the Dutch public health system as suffering from severe or extreme dementia. Averaging 83 years of age, they are cared for by around 250 staff - mostly qualified healthcare workers, the rest given special training, plus local volunteers. They live, six or seven to a house, plus one or two carers, in 23 different homes. Residents have their own spacious bedroom, but share the kitchen, lounge and dining room.´

This controlled care setting for dementia patients creates an environment where patients can live a life that is as close to normal as possible, but with safety and dignity reassured. Alongside their personal apartments are shops and facilities as you might find in a village, where care givers serve patients whilst monitoring and assisting them, implicitly.

http://www.theguardian.com/society/2012/aug/27/dementia-village-residents-have-fun

The King’s Fund (England)

´The environments in which we live and work have a profound influence on our physical and psychological well being. Research has repeatedly confirmed that a supportive and welcoming environment can have positive effects both on those who visit hospitals – whether as patients or their loved ones – and those who work in them.´

The King´s Fund Enhancing the Healing Environment (EHE) Program engages frontline clinical teams, facilities staff, patients and families in improving the patient experience through environmental redesign. Their improvement projects in the area of end-of-life care show how a set of core interior design principles and high levels of commitment and enthusiasm, can bring about measurable improvements to service quality and experience.

http://www.kingsfund.org.uk/publications/environments-care-end-life

Flinholm Retirement Home (Denmark)

´Flintholm Care Home is a five-storey ellipse-shaped building complex with fifty dwellings for elderly people. The top four floors are used for residential purposes, whereas the ground floor contains the main entrance area and all service functions and staff facilities, along with access to a park.´

This Home has been designed with the overall theme of ´focus on community´ which is expressed through several features of a design that manages to promote sociability whilst preserving privacy. There are very few conventional hallways and corridors. The oval footprint of the building allows individual housing units around the periphery to open into a central communal space, public space is on everyone´s doorstep.

http://m.dac.dk/en/dac-life/copenhagen-x-gallery/realized-projects/flintholm-retirement-home/

A Poppy’s Funeral at any crematorium is £1,750 + cremation fee

A Poppy’s Funeral at any burial ground or cemetery is £1,550 + burial costs

A Poppy’s Funeral gives you the opportunity to hold a family-led funeral at any crematorium, woodland burial ground or cemetery in the Greater London area.

Poppy’s Simple Funerals (England)

´We take pride in providing the down-to-earth, practical, emotional and highly professional service you need when faced with the death of someone you love. Above all, we care hugely about getting it right for you.´

A simplified funeral service with clear, understandable and accessible communication. Poppy´s offers a personalised and flexible service, taking a step-by-step approach that guides people and demystifies the process. Prices are kept transparent at all stages, appearing directly on their homepage. The visual identity breaks away from that of the typical funeral home, not black and sombre, but lively and colourful.

http://www.poppysfunerals.co.uk/

Dumb ways to die (Australia)

Dumb Ways to Die is a public service announcement campaign by Metro Trains in Melbourne, Australia to promote rail safety. The campaign went viral through sharing and social media starting in November 2012. According to Metro Trains, the campaign contributed to a more than 30% reduction in “near-miss” accidents in the first quarter after launch.

What is unique about this example of communication design is the use of black humour, cute characters and a catchy theme song to speak about death. The fun and humorous tone-of-voice of the campaign flips stereotypes about how to address public health and safety issues - fear and shock tactics are the norm. It´s fresh, memorable and effective.

http://dumbwaystodie.com/

Macmillan Cancer Support (England)

´One in three of us will get cancer and it’s the toughest thing most of us will ever face. If you’ve been diagnosed with cancer, or a loved one has, you’ll want a team of people in your corner supporting you every step of the way.´

Macmillan cancer support services provide practical, medical and financial support to patients and their loved ones. They are also advocates for better cancer care, spearheading fundraising campaigns. They recently revamped their communication design and identity, including changing their typology?font? to be more playful in order to attract a younger generation of volunteers and fundraisers. They provide a range of online fundraising tools (posters, stickers, digital banners etc.) that volunteers can download and use to design and promote their own local fundraising initiatives.

http://www.macmillan.org.uk/Home.aspx

THE PROJECT PROCESS

WHAT DID THE PROJECT SET OUT TO ACHIEVE?

- To understand the human needs, values, hopes and fears at the end-of-life for patients, their loved ones and professional care givers.

- To map and respond to the socio-cultural trends that will shape the end-of-life care landscape in the next 5-10 years.

- To identify opportunities to transform the hospice care experience through innovative new products, services and spaces.

- To create a new service experience blueprint to guide and inform future hospice design.

- To communicate this new vision of hospice-based care and help shift perception of palliative care in society and in healthcare.

WHY APPLY A DESIGN THINKING APPROACH?

Hospice and end-of-life care is a complex domain containing multi-faceted, systemic problems and constraints. Its characteristics create specific challenges for innovation: The human experience is at the core of this fundamental healthcare experience and includes not only physical but also emotional, social and spiritual health aspects. Multiple stakeholders interact with one another over time - patients, loved ones and care providers. Healthcare experiences can take place across a variety of contexts, from hospital to home.

Design Thinking is a systematic, collaborative, immersive and visual process.

Experience design is a specialist design discipline that combines product, service, interaction, environment and communication design. It is particularly suited to healthcare innovation since it can create systemic solutions that help transform a healthcare experience by improving the quality and consistency of that experience over time and across multiple touch points for the different stakeholders involved. Experience design can complement an architectural design approach, adding insights on the level of human experience and behaviour and helping understand how different elements of an experience - products, services, environment, signage - can combine to impact the way people perceive and experience care.

A Design Thinking approach enabled the team to unpack the complex challenges in hospice care and reframe them in the broader context of end-of-life and death care. Design Research helped to understand the issues and needs in-depth, and create empathy with which to identify new opportunities and generate new concepts.

WHO WAS INVOLVED IN THIS PROCESS?

12 patients, more than 30 care givers, 3 administrators, 7 loved ones, 8 volunteers etc.

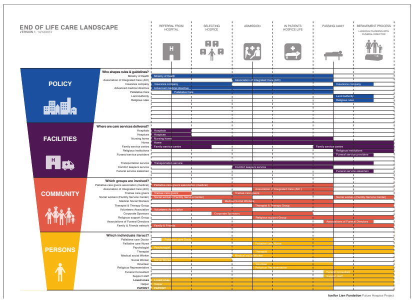
3 local hospices

1 funeral home

6 local domain experts

6 fuelfor designers

HOW DID YOU CREATE THIS DESIGN VISION?



FRAMING & SET UP

Defining the specific objectives, expectations, scope and boundary conditions of the project. Collating existing insights and knowledge and capturing assumptions to be checked through design research. Setting up an innovation framework and journey from referral to bereavement.

UNDERSTANDING & DESIGN RESEARCH

Series of 5 domain expert interviews and broad topic desk research. Designing of sensitive research toolkits in collaboration with hospice teams. Recruitment of patients, families and staff to participate in research. Site visits to 3 hospices and 1 funeral home to conduct interviews, shadowing, co-creation sessions and observations.

SYNTHESIS & ANALYSIS

Cluster analysis of insights to define common and distinct themes across all 3 hospices. Visual journey mapping to see how needs and issues play out over time from referral to bereavement. Refining and creating frameworks of understanding to facilitate the design phase.

DESIGN WORKSHOP

5-day design workshop with core design team to immerse in insights and frameworks of understanding e.g. hospice care journey. Brainstorming and sketching to generate ideas and identify and name a set of key opportunity areas.

FEEDBACK SESSIONS

Sharing and evaluation of concepts and overall strategy with care teams and experts involved in the original design research. Prioritisation, enrichment and development of ideas to define final set of concepts and focus strategic direction.

COMMUNICATION

Articulation of design strategy, vision and concepts in a design hand book. Prototype development to create props for the media launch event experience.

APPENDIX

To download appendices please visit...
www.fuelfor.net/fuelfor/hospitablehospice.html

ISSUES & INSIGHTS OVERVIEW
INSPIRATION BOOK
TRENDS
REFERENCES
FUNERAL RITUALS INFOGRAPHICS

www.thecarelab.org

Building upon 20+ years of health and care sector innovation, The Care Lab is an international network of designers initiating a movement to transform Care.

Their work drives change at both a local level in communities, as well as globally through international initiatives that apply human-centred design practices in the health, social and education domains.

Based in Barcelona this specialised team has a strong track record of design-driven care system and service transformation in Singapore, having worked extensively with the public, private and third sectors there since 2010.

In 2018 their work with National Council of Social Service Singapore won the prestigious P*DA.

www.lienfoundation.org

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It breaks new ground by investing in innovative solutions, convening strategic partnerships and catalysing action on social and environmental challenges. The Foundation seeks to foster exemplary early childhood education, excellence in eldercare and effective environmental sustainability in water and sanitation.

In its mission to advance eldercare, the Foundation advocates better care of the dying. One of its flagship programmes, the Life Before Death initiative, was first conceived in 2006 to create greater public awareness about end-of-life issues in Singapore. It sought to de-stigmatise death and dying by spurring various ‘die-logues’ with the use of social media, art, films and photography and advocacy though research. The initiative has since gone beyond Singapore. In 2010, the Foundation commissioned the first-ever global Quality of Death index ranking 40 countries on their provision of end-of-life care.

www.acmfoundation.sg

The ACM Foundation is an independent, non-profit organisation formed by Ang Chin Moh Funeral Directors in commemoration of its 100-year heritage. The Foundation aims at enhancing the perception of death and bereavement among the public, uplift the deathcare profession and advance philanthropy in this area. The ACM Foundation will also champion and preserve the heritage of funeral and bereavement services in Singapore.

We would like to thank all of the patients, families, experts, care teams and facilities with whom we collaborated in this project, for being open to share their stories and experiences, ideas and opinions and enabling us to propose a new vision of hospice care for Singapore.

> "YOU MATTER BECAUSE YOU ARE YOU, AND YOU MATTER TO THE END OF YOUR LIFE. WE WILL DO ALL WE CAN NOT ONLY TO HELP YOU DIE PEACEFULLY, BUT ALSO TO LIVE UNTIL YOU DIE.”

Dame Cicely Saunders,
founder of hospice movement

The Care Lab in partnership with the **Lien Foundation & ACM Foundation**