a little pocket book

for head and neck cancer patients and caregivers

by head and neck cancer patients and caregivers

supported by

The Swallows®
Head & Neck Cancer Support Group
Registered Charity Number: 1149794

MACMILLAN CANCER SUPPORT

this little pocket book
is made with love

by *us* for *you*

created and compiled by

Gillian Muir

produced by

The Swallows
Head and Neck Cancer
Support Group

supported by

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Funded by
MACMILLAN
CANCER SUPPORT

When I was told ‘you have cancer’ it took the feet from beneath me. I knew no one else who was on a similar journey. This little book is a compilation of quotes from patients, survivors, caregivers, friends and family members, sharing what we know now but wished we had known when we were first diagnosed, through treatment and beyond.

No one should feel alone.

Gillian Muir

thyroid and tongue base cancer survivor

These quotes, tips and hints are the opinions of those who contributed them.

They are not in place of medical advice. Always consult your medical team about your personal cancer journey.

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A swallow
is a symbol of
many things

hope, love,
family, protection,
good luck and new
beginnings.

from diagnosis to treatment

PATIENTS

“It takes time to find out all the pieces of your cancer diagnosis. It’s like pieces of a jigsaw. A jigsaw that changes as more tests are carried out.”

“Talk to your loved ones. Cancer shouldn’t be a solo journey.”

"I felt devastated when I was diagnosed with cancer. Don't isolate yourself. Let your friends and family in. Let them know how you are feeling and let them know how they can help."

"Join a support group. You are not alone!"

"It's a journey but it's your journey."

**“You are not your illness.
You are a collaborator.”**

**“Do not Google!!
Get information from a
reliable source. Ask your
medical team.”**

“Carry a notebook with you and write everything down. Any questions, any thoughts you have and ask the health professionals.”

“When you are diagnosed with cancer you will be changed but you will still be you.”

“It’s good to talk to others who have or have had cancer but remember no two cancer journeys are the same.”

“Sometimes it felt like I was standing on a burning platform.”

“Take one day at a time.
Listen to your body.”

“It’s okay to not be okay.”

“You have got to have
hope at this stage of your
journey.”

“Deal with it as well as you can. Remain positive and look to tomorrow, whilst living for today.

You will get through it. This is just a lump (or two) on the road of life. Above all, smile all you can, whenever you can.”

“All I can say is trust the consultants and nurses. They know what they are doing. Ask any questions, however stupid. They will have heard them all and know the answer, or know someone who does.”

“The period from diagnosis to treatment was mentally the most challenging phase. Uncertainty, fear and anxiety. I got through it. You will too.”

“Take someone with you to appointments. Two pairs of ears are better than one.”

“Ask as many questions as you need to throughout and don’t be afraid to ask them again.”

“If you feel like screaming then scream.”

“It’s okay to feel low.”

“Never give up hope.”

“Don’t panic. There are many people further along the journey who can help and support you.”

"Get hold of a notebook and write on the right-hand page all the good things that have happened that day. On the left-hand side write all the negative things. Your brain will remember the right page and forget the left page and you will start to feel more positive. If left-handed it is the opposite way round."

“The worst part for me was not being believed and not getting people to listen to me. You know your own body, be vocal, be strong and believe in yourself.”

“There are several different types of scans you may have. I wanted to know what to expect before I went. Others just went. Ask the nurses if you want to know.”

“My old mum always told me to count my blessings. So I started to do that and it helped.”

“I was worried about money. Find someone to talk to for advice and financial support.”

“The hardest thing for me was the waiting.

Waiting for appointments.

Waiting for results.

Waiting for treatment.

You just have to learn to be patient.”

"When the dark thoughts crept in, I went to bed and pulled the covers over my head. Then I decided to put on my jacket and get outside for a walk, listen to the birds, watch the sunrise or sunset. Connecting with nature and getting out the house helped me."

“The journey may seem long but remember there are so many people around you who will help you along the way to the better place you are seeking. Some you already know and some you haven’t met yet.”

“When I was waiting for my diagnosis, I looked upon it as a wake-up call. I decided to make positive changes. To take some control back. I stopped smoking, reduced alcohol intake and engaged in physical activity. I also found a support group and thought about nutrition.”

“Find your own coping strategy. Not everyone wants to be in a support group. Find out what works for you.”

“Don’t feel guilty for feeling hard done to.”

“I felt guilty that I was putting my family through this, especially the kids. I tried to be brave. I think they saw through my bravado. Find someone to talk to.”

“I found it hard that some people I knew well ‘ghosted’ me when they found out I had cancer. I think they didn’t know what to say to me. Those who did reach out were worth their weight in gold.”

“Utilise your doctors and nurses. There is no such thing as a stupid question.”

“Ask for leaflets on your type of cancer from the nurses, if you haven’t already been given them.”

“Being kept waiting at clinic appointments was very stressful. I took a book or crossword to keep me occupied (Wi-Fi came and went). These helped but it was still a hard wait.”

“Laughter sometimes is the best medicine.”

“You are starting on a new journey. No one says it is going to be easy, but get prepared for the road ahead.”

“Be kind to yourself.”

during treatment PATIENTS

**“You are not your illness.
You are on a trip through
your illness.”**

**“Radiotherapy and
chemotherapy are tough.
Toughest thing I’ve been
through. But it did the trick.
I’m still here.”**

“I had several operations to remove tonsils, laser tongue dissection, neck dissection and my thyroid removed. My husband ordered silicon moulds for ice pops that he filled with fruit squash and froze. They were a godsend and gave me relief in my mouth and throat.”

“As a patient for 30 sessions of radiotherapy, I learned the words to The Wonder of You (Elvis Presley) and sang it to myself in my mask. Listen to the words of this song and you will realise how this got me through my treatment. Thank you, Elvis!”

“Book small moments of joy like the theatre, a concert or a walk.”

“Keep on keeping on.”

“Count your breaths during radiotherapy. I did 10 per finger. I knew when I got to 11 fingers the session was about to end. Several weeks in I was practically falling asleep during it.”

“YOU WILL GET THROUGH IT.”

“For me the period of treatment was the most challenging. Keep going.”

“Stay active.
Keep exercising.”

“Be positive. My reason to go on was my lovely family.”

“I had radiotherapy. Apply plenty of cream to the targeted areas.”

“No need to strain your voice. Write things down, use technology.”

“Keep a diary to record progress and look back at it in the weeks ahead to see how well you are doing.”

“Make a checklist of what you want to do on the other side. Set achievable goals to head towards. For me it was to get a new motorbike.”

“Sleep if you feel you need to.”

“It’s okay to feel low. But not for too long.”

“When I found swallowing difficult, I used baby cutlery. Smaller mouthfuls of food were manageable.”

“Keep swallowing. If you don’t use it, you’ll lose it.”

“There are many products to help with voice and swallowing. Ask a nurse or a support group like The Swallows.”

“Get yourself a soup maker and a blender.”

“If you take tablets orally, but are struggling, try taking them with a spoonful of yoghurt.”

“Things change quickly. Your needs change. Take it a week at a time.”

“I found the whole experience overwhelming. Set goals for each hour. Plan distractions. Fill your time. You are not alone.”

“Freeze the drinks like Fortisip into ice cubes. Add them to other Fortisip drinks for a really cold drink. That helped me.”

“Try to keep a sense of humour, even in tough times.”

“Don’t be afraid to tell the hospital about any side effects of treatment. There are plenty of things available to help alleviate symptoms.”

“Put your cream in the fridge when experiencing radiation skin reaction.”

‘It’s okay to feel like shit. Watch a box set or two.”

“Radiotherapy sessions don’t take that long. The team are great and put you at your ease. You actually miss them when your stint of treatment is over. The team that is, not the treatment!”

“The mask is your friend not your enemy. It could save your life.”

“Try to keep your daily life as normal as possible. Gentle exercise and plenty of rest.”

“Think about what kind of music you might want to listen to when getting radiotherapy. Waiting to go in, you sometimes hear what others are listening to from hard rock anthems to classical music. I chose the Lion King. Hakuna Matata did it for me.”

“I was terrified of wearing the mask as I am claustrophobic. I got a call from a radiotherapist a couple of weeks before treatment started. She talked me through it and was also there on my first day. Don’t underestimate the medical team. They know what they are doing.”

“They asked me if I wanted my mask after my treatment. I said no. Some people take it and make art out of it. I held it in my hands and thanked it, then handed it back.”

“I thought I would be in a small room with the door closed for my radiotherapy treatment. In reality the room has a barrier but no door. It was airy and spacious.”

“In preparation for my radio iodine treatment in an isolation room, I selected podcasts to listen to, craft activities, colouring-in books and books to read. Isolation gave me time to write lists of things I wanted to do and take stock of my life. It wasn’t so bad to take time for myself.”

“My daughter gave me a wooden box and had stuck the letters MUM on the lid. In the box, she and her brother had filled it with 30 envelopes, one for each of my radiotherapy/ chemo treatment days. In some envelopes there were photos of special times, in others the odd poem, a lip balm, a QR code to take me to comedy clip and a selection of small and well-chosen books....

...Both children lived far away from me, but they said that knowing I would open an envelope every day helped them, knowing that they were sort of with me. It really meant the world to me."

“Find the things that make you smile.”

“I was able to use a liquid diet or blended diet down my PEG tummy tube. Speak to your dietician and you too can *join in the family meal*.”

“I filled an empty 2 litre plastic bottle with water every morning and set my goal to drink it all by bedtime.”

“Find something that helps you get through this. I got up every morning to watch the sun rise and listened to a guided meditation session. I’d never meditated before but found it to be a calming experience.”

“People said how brave I was during my treatment. I wasn’t brave. I had no choice, but I got through it.”

“It’s a scary time filled with the unknown. Put your trust in others who are helping you.”

**“Follow your journey.
All in good time.
Everyday will be different
but don’t forget to shine.
Head for the finish line!
You can do it.”**

“Have a positive mental attitude, despite how bad you feel. For 33 days throughout chemo/radiotherapy I went dressed in bright clothes as though I was going on a lovely day out. I didn’t want to look as bad as I felt. It brought a smile to the nurses’ faces.”

“When friends and family offer help it is because they genuinely want to help. Let them help. In my case they took turns to drive me to hospital so my husband could go to work and have some sort of normality.”

“When swallowing is hard a blender is your best friend. Mix up milk shakes, adding exciting ingredients, fruit, cookies, cream and ice cream for a delicious smoothie.”

“If you have a feeding tube and find it hard to get the fluid out of your stomach to do the ph test then stand up and touch your toes several times. That worked for me.”

"If you are going to spend your time thinking, choose the happy positive path to stroll down. Take your imagination off to play when things feel tough. Choose light, bring in love to your heart, choose all the gratitude for the smallest things, wear colour, put on music, move, dream, hug."

“Remember who you are. You can get through this.”

THE SWALLOWS 24/7 PATIENT & CAREGIVER SUPPORT LINE SERVICE IS ANSWERED BY A REAL PERSON

☎ **(+44) 07504 725 059**

TEXT (LARYNGECTOMY ONLY): (+44) 07830 929400

You can find information and support from The Swallows Head and Neck Cancer Support Group by visiting:

www.theswallows.org.uk

or emailing:
info@theswallows.org.uk

after treatment PATIENTS

“Take each day as it comes. Don’t be impatient. Progress can take a long time but always look back to see how far you have come, not how far you have to go.”

“Recovery might be slow but be patient and celebrate the small steps.”

“Avoid making comparisons on how things were before diagnosis.”

“Recognise the improvements you have made and value them.”

“Everyone’s recovery journey is different, so don’t compare yourself to others.”

“Things will never quite be the same as before. That’s not all bad. Embrace the new you and new way of living.”

“Listen to your body. Pace yourself for the future.”

“Looking back on my cancer journey, it has made me realise how much I am loved. I knew my family and friends loved me, but I didn’t realise how much. I felt great gratitude like never before.”

“Prepare for new adventures.”

**“Go easy on yourself.
Don’t run before
you can walk.”**

**“Cancer changes your
life, sometimes for the
better. You learn what’s
important, what to
prioritise and not to waste
time. Seize the day.
Live life to the full. Smile.
Tell people you love them.”**

“Try to keep positive. My consultant said that a happy patient is a healthy patient.”

“Oral hygiene is important. Get a water flosser to add to your dental routine.”

“After treatment you will get regular check ups. If anything is worrying you between these appointments, contact your hospital and ask them. Don’t wait for next appointment.”

“Forward planning is the key when you feel ready to go out for a meal. Phone ahead and ask restaurants if they can cater for your needs. Ask if they can give you more gravy or sauce or adapt what is on the menu.”

“Investigate all the products for dry mouth. Many companies send samples. If one doesn’t work, then try another.”

“This is a new opportunity to experiment in the kitchen. There are wonderful cookbooks available for head and neck cancer patients.”

“It’s happened or
is happening.
You can’t take that away.
Live for the moment.
Learn to live how you are.”

“Don’t be put off. One side effect from my treatment was now not being able to project my voice. Before going somewhere, let people know this. If you tell people in advance, it can avoid awkwardness.”

“Request a sample box from The Swallows. It will help you find the products which work best for you.”

“Stay positive.”

“Live for the day.”

“It’s all about small victories and wins. Truth is, you will be monitored for the foreseeable…but you get used to it. Don’t forget to enjoy the victories when they come.”

“A cancer journey is tough. Is it really all over? Flashbacks, tears and fear still come. I try to look to all the good things in life. Look forward, not back.”

“The worry never really went away. The worry of cancer returning. I’ve slowly learned to seize the day. Worrying never helped anyone.”

“Take each day as it comes.”

“When you have finished your journey and been given the all clear from the consultant, arrange how you can get back in touch should you need to. Find a way to have direct contact with dentist and H&N specialists. This way lies peace of mind.”

“Now I tackle problems that arise differently. I say to myself, ‘If I can get through my cancer treatment, I can get through this.’ I feel like a warrior!”

“Go forth and have some fun.”

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from diagnosis to treatment

CAREGIVERS

On the day that my wife, Jo, received the news she had cancer and needed major surgery, both of our lives changed in an instant. I had to learn quickly to enable me to support her through the surgery and all that followed. It was far from easy as we shared the voyage to develop a new normal.

Not all of the changes have been negative. We have learnt to appreciate our opportunities much more. We have made many wonderful friends and now have the privilege of supporting others through The Swallows.

The following quotations are from caregivers, family and friends of head and neck cancer patients and survivors. Sharing our experiences will highlight that others have trodden the same path. You are not alone. Never underestimate your importance.

Andrew Hyde

Caregiver to Jo

“It is the most frightening thing to be told your loved one has cancer.
You suddenly feel very alone. Find a support group. That way you have someone to talk to and are never alone.”

“My wife is 15 years on.
Stay positive.”

“As a caregiver, I needed to make sure I knew what was happening and coming up. My wife (patient) didn’t want to be told about anything coming up more than a few days ahead.”

“A caregiver is allowed to feel down, sad, fed up with it all. They also didn’t choose this journey!”

> “Go with your partner to all appointments and don’t be afraid to ask your own questions to clarify in your own mind what you have just been told. Between the two of you there will be both understanding and a memory of what you have been told.”

“When you are in the waiting room you might not feel like talking to others, and that is understandable and okay, but, if you did, it might help them and you when you least expect it.”

“Keep a notebook and write down any questions and concerns you have so you can ask the medical team at your next appointment.”

“It is only natural that the mind can go down a negative path. As caregiver, you need to find ways to, at best, stop this and turn it to positive or even just neutral.

That might mean just not responding to the negative, but without being perceived as dismissive, not listening or non caring.”

“Everyone is different, as you will be told by all, but there is a basic path you will follow.

Diagnosis, forming plan for treatment, treatment, short term recovery from treatment, review of treatment, forming plan for any further treatment, short term recovery from further treatment, review of treatment, long term recovery and monitoring.”

“Stay positive. You will be given lots of information to read. Keep it to hand and go through it bit by bit. Don’t forget to revisit this information throughout the process. You won’t remember it all at first.”

“Talk to people. Tell them how YOU feel. It’s not selfish to do so.”

“When my Mum was first diagnosed, I didn’t tell anyone. I buried the worry and hid it from work colleagues and friends. Then I chose a couple of friends to confide in and that really helped.”

“Nobody is an island. It’s good to talk.”

“When my best friend told me she had cancer I held back the tears and told her that we were in this fight together. We met every week as usual and shared the fear, the unknown and rejoiced in the fact that we had each other. Cancer was not going to come between us. Let your loved ones know how much they mean to you.”

“Nothing prepares you for your parent needing you in ways that you are needed. I’d say I’m quite tough, but it nearly broke me at times.”

“Cancer diagnosis, treatment and recovery is not a race but a marathon and may be 9-12 months before you are in monitoring.”

“There are pauses, delays and waiting times that can and will happen all through this. These can be anxious times. Some will fix themselves but if YOU feel like they are taking too long then they probably are! So don’t be backward at being forward and ask the professionals for assurance or action.”

during treatment
CAREGIVERS

"Be organised with the medications so you know what has been given and what is still to be given. A tick box sheet really helps."

"Diet and tastes will change and, after surgery, will mostly consist of fluids, ice cream and soft bland foods. Eventually you will find a way of having meals together, but it will take time."

“Keep stock of medications. Order requirements with plenty of time to spare.”

“If there is a procedure which you need to do, but you are unconfident, ask to be watched by one of the medical team while you do it. That’s the best way to learn.”

“Find a space somewhere in your house where you can keep all the medication set out in an organised way rather than them being still in the pharmacy bags. In other words, create a medication station.”

“Continue to see the funny side of life when you can.”

“Communicate with the Clinical Nurse Specialists (CNS) as they have more time than your consultant and are often practical in their approach. Mine were great!”

“If instructions seem impossible, don’t just soldier on. Explain this to the medical staff. They probably won’t have realised and will be happy to advise.”

“If your loved one has a feeding tube, you might be doing a lot of washing up (syringes etc.) get yourself some rubber gloves to avoid sore and chapped hands.”

“When asked how you are, don’t say ‘I’m fine’ - you won’t be, and it’s not selfish to say so.”

“Being a caregiver was hard and heartbreaking, but I just got on with it. There was no question of not being there for my Mum.”

“Nothing felt like conscious effort, autopilot kicked in, but at times I felt like the autopilot was dragging me along and I couldn’t catch up. My advice is: just keep going.”

“Try to have some normal time together when you can. Watch a favourite TV programme or play a board game. A small taste of normality helps to keep recovery in sight.”

“Make time for your own needs. The timetable for each day may well look very different, but to support your loved one you still need to ensure that you are fit and well.”

“There can be lots of things to do each day. It’s easy to lose track. Write a list of jobs for each day and tick them off. You can rest at the end of the day knowing that you have done what is required.”

“Take photos and keep a log of events. When things start to improve it’s easy to forget what you have been through. They will help you to realise the progress you have made.”

“If any part of your responsibility seems too much, or presents logistical challenges, tell staff at the hospital. They can’t help if they don’t know.”

‘It can be lonely being a caregiver.”

“As a caregiver you support them to listen to what their body wants and needs rather than what their mind and spirit is driving them to do. That does not mean stopping them doing things, just tempering the pace when the body needs to rest.”

“There are days when you can see a clear light at the end of the tunnel and there are others when the light is the train coming towards you.”

“It is unlikely the issue you experience will be the first time in the world, so don’t be reluctant to ask. It may feel it sometimes, but you are definitely not alone.”

“Learn which medications are to give relief to the direct side effects of radiotherapy and chemo, such as pain and sickness, and those which are to help the effects of the medication. This will help to give the right thing at the right time.”

“Hang on in there.”

“The various medications can have different timings during the day and night and when best to take them. To avoid further implications, or even cancelling one another out, learn from the doctors and nurses when best to take them. Find a daily plan that works for them and make a safe space for all the medications. Stick to a routine. It helps them and you to have this.”

“There are some medications that may be for life and there may be a period of almost trial and error to establish right amounts for them. Some days will be better than others whilst they stabilise.”

“Avoid giving them foods that contain natural acids such as citrus fruits as they can burn the throat.”

“Once they can tolerate liquids, they will start on bland soft foods. This is when the blender becomes your best friend!”

“To encourage my husband to drink more water, I too started to drink more water. It helped him and gave me lovely clear skin!”

“There are loads of products out there. Investigate what can help for dry mouth, etc.”

“No one will tell you this part of your caregiver journey will be easy. But you’ve got to have hope, and you’ve got to carry on.”

“It’s tough being the caregiver. If no one hasn’t already said ‘well done’ to you then I am saying it now. Don’t ever underestimate the job you are doing.”

after treatment

CAREGIVERS

“After treatment, especially radiotherapy and chemo, there may still be a long way to go until your loved one will start to feel like themselves again. Hang on in there, you have got this far!”

“As they get their appetite back make sure you make extra sauce or gravy to help them manage soft foods. Mash as much as you can.”

“As your loved one comes through the treatment and begins to improve, they will start to develop a new normal. Accept, and be part of, this process. Talk to others who have been through similar challenges. You will find a wealth of strategies and advice. Whilst every patient is unique, the individual challenges aren’t.”

“The journey is made up of many small parts. Notice the improvements that your loved one makes, point them out and celebrate them.”

“Stay positive.”

“It’s not selfish to feel stressed. The pressure on the patient is mirrored on you. Talk to someone who will listen. Unload. If you don’t want to talk to your family or friends, then find a support group. They will understand.”

“You’ve made it this far. Keep going!”

“In developing a new normal, your loved one might need to adapt their diet. Be flexible and join in with these adaptations. It will help make the new normal feel normal.”

“Things may quite never be the same again. Embrace the new way of living. There are loads of negatives of the journey you have taken together but try to think about the positives.”

"It is not unusual to feel overwhelmed with what has just happened in your life. Take your own time to process it."

"Allow yourself to think about what the future now holds. Make some plans."

“Carpe diem!”

A big thank you to everyone who contributed quotes to this little pocket book and to you for reading it.

thanks also to
Alastair
Chris at The Swallows
The Swallows Team
Andrew and Jo
Abbie
Southampton General Hospital

You are wonderful caring human beings.

Thanks also to our sponsor MacMillian Cancer Support

Funded by
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Head and Neck Cancer Charity

This book has come about by the support given from this charity. Chris and his team are dedicated to helping patients and caregivers. They offer their unrelenting time and expertise. It is a tough time for charities at the moment. If you would like to make a donation, however small, it would be greatly appreciated and put to good use.

You can do so at
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The Queen's Award
for Voluntary Service
The MBE for volunteer groups

SCAN TO DONATE

a little pocket book

This book is for those on a head and neck cancer journey or for a caregiver to someone who is. It's packed full of tips and quotes from others who have trodden this path.

It's not a journey any one of us chose to take, but it can be helpful and comforting to know that you are not alone.

This little pocket book was made by us with love for you.

We hope it helps you on your own journey.