Pain and Palliative Care Unit, Department of Paediatrics,University Malaya Medical Centre

You are not *alone*

Advice from Parents of Children with Serious Illnesses

Edited by Chong Lee Ai and Farah Khalid
Illustrated by Liz Loo

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Acknowledgement

The Parents
En Irwan Bin Ismail and
Puan Nor Rieza Binti Bujang
Puan Naima Yuzi bt Mohd Yat
Ms Yeoh Mee Cheng
Ms Bobo Shin

The Children
Adam bin Irwan
Muhammad Akmalrul Haikal binAffizan
Chen Kun Nam
Hiew Yu Ten

The Writers
Ms Angeline Ng
Dr Wong Soak Koon
Dr Farah Binti Khalid
Dr Chong Lee Ai

The Illustrator
Liz Loo

You are not alone

The sun is shining, not a cloud in the sky, your child is outside playing or happily chatting with you. Then you notice your child is not well. Perhaps the illness has lingered for a while or sometimes there is no warning. Your world would be turned upside down when you learn that your child could be suffering from a serious or life-threatening illness.

It can be very scary and as parents, you feel helpless as you watch your child become more ill and not quite herself or himself anymore. We hope this booklet will help you regain some control over your situation and offer some insights into your journey as you care for your child. Remember you are not alone.

During Diagnosis

When you first learn that something may be wrong with your child, you feel shock, disbelief, or even anger that this is happening to your child and your family. It doesn't seem fair. It is also very natural to feel fearful and to cry a lot. The important thing to know is what you are not alone and that help is available.

● ● **DIAGNOSIS**

The diagnosis is the first step to ascertain what is happening to your child.

Do research where to go and which specialist to see.

Ask someone you trust like your family doctor or family members and trusted friends for referrals or suggestions.

Depending on your child's condition, hospitals with specialists (eg. PPUM) are highly recommended because the specialists available specialise in many areas.

ASK
ENQUIRE
SEEK CLARITY

When you meet with the doctor or specialist to receive the diagnosis, do not be afraid to ask questions. Get as much information as you can from the doctor. Sometimes the doctor can be very technical. Or sometimes the doctor does not give you enough information.

If you are not sure about any details, ask the doctor to explain again in simple terms what the diagnosis means and how your child will be affected by the illness. Ask what treatment is proposed, and whether there will be side effects, and how long the treatment will last.

You will be tempted to google or search the internet for more information about the illness-that is natural. However, be very careful to use reliable, trusted google sources. After these searches, ask the doctor for more information if you have any further questions.

Talking to your child

One of the hardest steps is talking to your child, especially to a small child. Nonetheless , you need to explain what is happening to your child.

Try to use simple terms so that the child can understand what is happening. Include your teenager if you think they would want to know what is going on, it's less frightening for them.

Reassure the child that the doctors are doing their best and that the medical team will focus on the child's well-being.

During Treatment

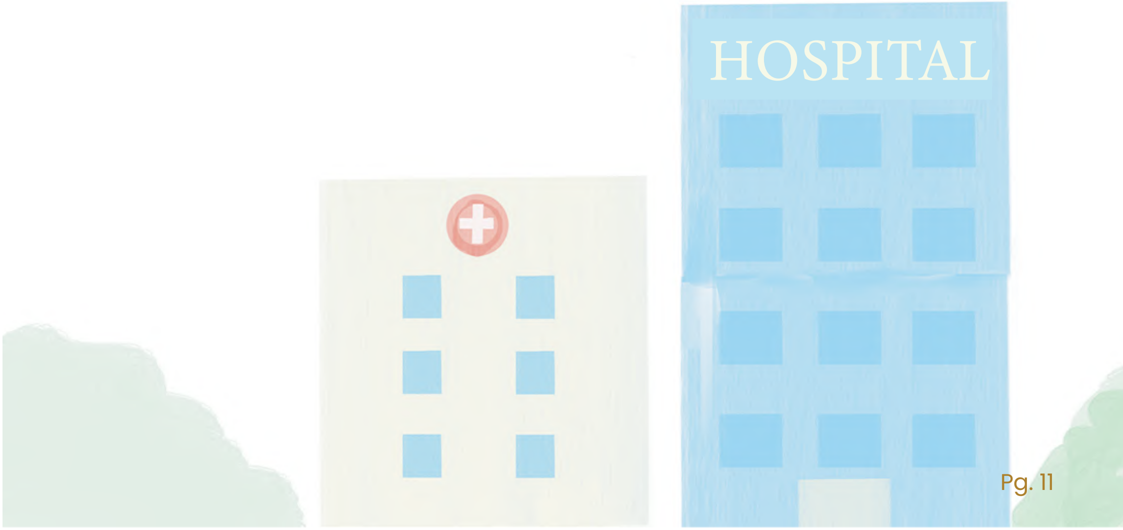
Treatments and procedures like MRI, CT scans, biopsies, blood tests and other procedures will follow. This could be scary for the child, and even for you as parents as you see your child being hooked up to different machines or having operations. Your child may need ‘central lines’ or ‘chemoports’ so that medicines can be given directly without them getting ‘poked’ frequently.

Medical procedures to determine progress of the disease and treatment.

Though these procedures and medical equipment can be alarming, follow the advice of the doctors and undertake these treatments or investigations as soon as possible.

These scans or procedures are essential for the doctors to make informed decisions, for example, to ascertain how far the illness has progressed, and from there, to decide on the next course of action to fight the illness.

Often parents will seek a second opinion to verify the initial diagnosis. However, once you have verified the initial diagnosis, do not delay the treatment recommended by the specialist.
Delay can cause the illness to worsen.



We are here for you and your child

Alternative and traditional Medicine: Caution

Family members or friends may persuade you to try alternative or traditional medicine to treat the child. All these options can be confusing. Discuss these options with your doctor first.

If your doctor says there is no harm to proceed with certain alternative or traditional medicine, then you may do so. However, it is important to trust your doctor or specialist and follow their advice.

ASK
SPEAK UP
COMMUNICATE

Information during the treatment process is very crucial. Do not hesitate to ask the medical team for more information. Encourage your child to give feedback directly to the medical team too.

If you feel that something is lacking in your child's care or treatment, speak up and if a medication is not suitable for your child, explain your reasons (for example an allergic reactions or very adverse side effects to medication), ask for clarification from the medical team.

Similarly, if you think the doctor's assessment or treatment is not so helpful, ask the doctor if there are alternatives.

Dealing with the family's challenges of caring for patients

Treatment can be exhausting for both the child and the parents. Multiple trips to the hospital and even extended hospitalisation will be required.

It is important for the parents to be prepared mentally for these lengthy hospital visits, and to determine how to best care for the child.

If you have other children at home, parents should work out a schedule so that, if possible, perhaps one can be the full-time carer of the sick child, while the other focuses on the other children at home.

If you are a single parent with other children at home, this will be challenging for you to juggle the care of your sick child and your other children.

Family support will be very important. If possible, seek additional support from your extended family, neighbours or other community/religious networks. The hospital and medical staff are usually very supportive of parents too.

Try to remain positive at all times and banish negative thoughts . For believers, of whatever religion, prayer helps.

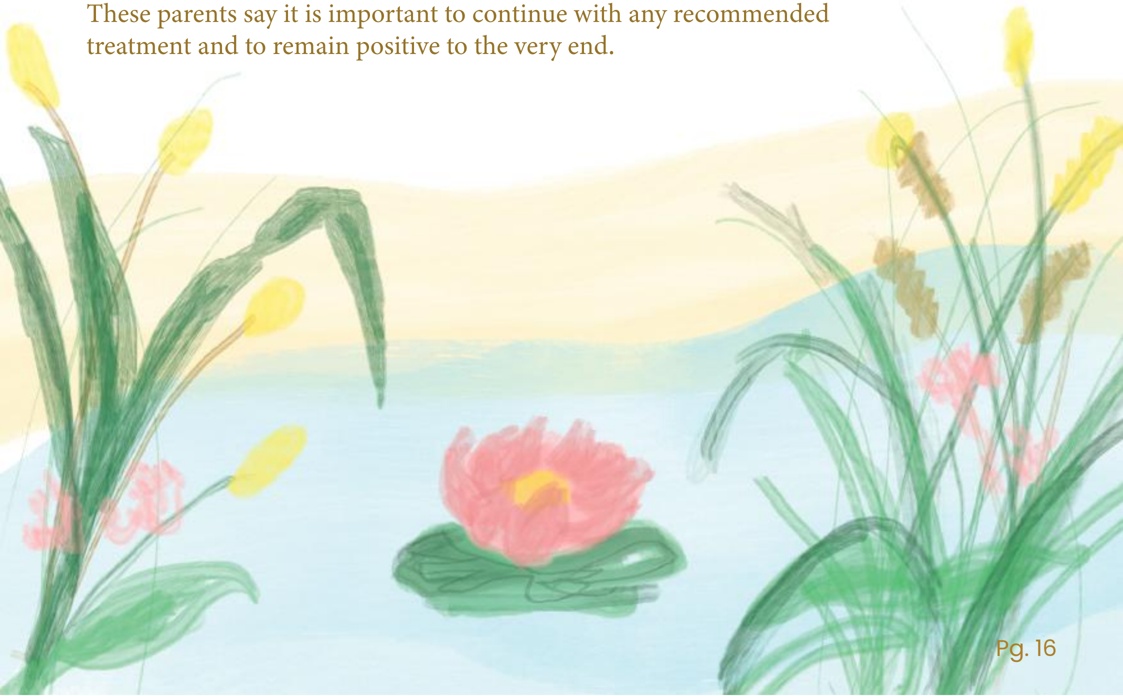
When things don't work out as planned...

Parents should always maintain open and honest communication with the specialists and medical team, so that the parents can be prepared.

You may be referred to the Palliative Team when the serious illness is diagnosed or when things don't work out as planned. The Palliative Team can provide further practical, psychological and emotional support during this difficult period as the team will check on both your child and you as parents.

Besides the Palliative Team, parents may find much needed relief speaking frankly to trusted, caring family members and friends. We are all human and there are moments when we need to speak out our pain yet remain hopeful.

Parents who have been on this journey say that at this stage, their focus is on ensuring the comfort and happiness of their child. These parents say it is important to continue with any recommended treatment and to remain positive to the very end.



Parents have shared that when things don't work out as planned, they focus on their blessings – that they have been blessed with a beautiful child and had the opportunity to care for and love their child for such time as is determined by God. They feel no regrets because they have done their very best for their child.

The journey is a tough one for parents as it is difficult to see your child in pain or suffering or in discomfort. It is important to keep communicating with each other and support each other as you make this journey together with your child. Reach out to the Palliative Care Team if you need someone to talk to, and do not be afraid to ask for help.

Notes

* We Care Because You Matter *

MyStarfish Bhd. (201901028151) is a non-profit organisation set up to empower children and adolescents with incurable or serious illnesses, and their families, to live fulfilling and meaningful lives. MyStarfish Bhd. is privileged to be associated with these parents who have been brave to honour their children with this sharing their experiences.

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