

When a Child *Has* Serious Illness



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Serious
Illness

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Living before Leaving

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Foreword

As a group of professional providers supporting children with serious illness and their families in hospital and hospice, we often struggle to locate supportive resources that fit the local context. Although tensions and emotions involved are similar, cultural differences limit meaningful translation of many self-help materials widely available on the web.

It is precisely this quandary that motivated us to produce our very own family caregiver guide.

This brief collection is targeted at parental or family caregivers who have children diagnosed with life-shortening illness, whether referred to palliative care or not. It brings to light the experiences of many families who have walked this path, and offers practical tips for newcomers who are starting their own journeys.

Loosely organised according to stakeholders and anticipated tasks along the way, it can be consumed in whole or in parts. Meanwhile, readers are invited to speak with their own providers to learn more or if further information is desired.

Singapore Hospice Council is grateful to all chapter contributors who have generously shared their expertise and time in putting this guide together. We foresee this first initiative heralding publication of even more resources that Singaporean families whom we support can find comfort in.

DR CHONG POH HENG

Vice Chairman

Singapore Hospice Council



Supporting Yourselves as Parents

By Dr Teresa Tan and Victoria Ng

Hearing that your child is seriously ill is likely the most difficult time in your life.

Some parents feel that acknowledging that their child might die is a sign that they are giving up. Others want to know, to prepare and make decisions given the situation.

Everyone is different, and will hence respond and cope in their own way.

We will share how some families managed similar situations and hope this will be of help to you.

How Families Begin to Prepare Themselves

Focus on the present. Take a pause and think about the emotions you are facing right now. These are not easy to bear, but it helps to acknowledge them.

“I thought we would all crack up, it all seemed so horrific... As time passed, we found ways to cope, things to spur us on, little things to grab onto, to focus on... I was amazed how we did cope, maybe we just had to.”

Mother of a 3-year-old boy¹

Allow yourself time to grieve. A “problem-solving” mode may end up increasing anxiety and a sense of helplessness. If the situation is too overwhelming, slow down, and just “be” with your child.

Reflect on what is most important for yourself, your child, and your family. What would give your child love and comfort at this point?

Have you previously experienced other losses - what was important to you and what helped you cope then? It may be helpful to pen down your thoughts and feelings. Speak with a close family member or trusted friend.

Conflict Is Common and Inevitable

Caring for a child who is seriously ill is extremely strenuous – physically, mentally, and emotionally. It seems almost practically impossible. While caring and anticipating the needs of your sick child, you can feel guilty for not meeting the concurrent needs of other family members. This can cause tremendous strain on relationships.

Most parents have found that it is important for them to be aligned – in their goals for their sick child and the family as a unit. Try and see things from each other’s perspective. Compromise as much as possible. Conflict and disagreements significantly add to your own burden, and may be noticed and carried by your sick child.



“I tried to plan what I would say to other people. It worked some of the time. Sometimes, the actual planning was enough for me to feel I could get through this... something to say, something to do...”

Mother of an 8-year-old boy¹

¹ Adapted with permission from the publication *Facing the Death of Your Child*, produced by Children's Cancer and Leukaemia Group (CCLG) - the UK's leading provider of accredited cancer information for children and young adults, and their families ■ www.cclg.org.uk. CCLG accepts no responsibility for the accuracy of this adaptation.

Most parents have found it useful to ask for help at this time from relatives, friends, or their medical team. It is alright to decline offers of support when you do not need it. It is also alright to ask for help later, when the timing is right.

“Why?” – A Question We Sometimes Do Not Have an Answer For

We all have questions at one time or another: *Why is this happening to my child? What have I done wrong? Why does my child have to suffer?* These thoughts are common and natural.

When someone we love is very ill and possibly dying, we can feel angry, confused or lost. Some families question their beliefs, while others may find their faith a great support at this time. Individual experiences and needs are different. Be patient with yourself. Answers to these difficult questions might not surface till later.

You may wish to talk to friends, healthcare staff, the chaplain or counsellor, or a suitable religious leader. Some people feel embarrassed asking about these things. However, most parents have found it valuable in discovering meaning and strength.

What Are Other Concerns at This Time?

Many parents worry that their child will be in pain. The medical team will do their best to ensure your child's comfort. Do engage them if you notice that your child continues to be in pain.

As your child gets weaker, they might eat less. This often puts parents in distress and causes them to feel helpless. It is a natural and expected change as your child's condition deteriorates. Your child is unlikely to feel hungry. Keeping their mouth clean and moist will bring much comfort.

“The most important thing was to be able to cuddle my child at the end. If I couldn’t do that, I would have felt like a failure as a mother...”

Mother of a 17-year-old girl¹

Your child may also appear more tired or be sleeping more. However, they are still able to hear and feel. Thus, your voice, touch and cuddles will be extremely comforting.

Some children and families feel most comfortable at home. Others feel safer in the hospital. If you have any thoughts or preferences on where and how you would like your child to be cared for during this time, discuss them with your doctor or nurse.

Practical matters, such as finances or support of siblings are common too; do not hesitate to discuss these concerns with the medical social worker on the care team, or a trusted family member.

Summary

- Nobody is ever prepared.
- Express love, pride, and gratitude; at the same time, maximise closure and minimise regret.
- Focus on what matters most to you, your child and your family.
- Stay together as a couple.
- Support is always available. Reach out to your medical team for help.



Communicating with Your Sick Child

By Dr Teresa Tan and Victoria Ng

It is difficult to decide when and how much to tell your child, or even if at all! There is no right or wrong in this matter. It all depends.

In this chapter, we share what has helped other parents and children in similar situations – whether to have this conversation, and how to go about doing it.

Should I Talk to My Child About What Is Happening?

Whatever you decide needs to be comfortable for you as a family. Many parents instinctively withhold information to protect their child.

We suggest speaking with your child, as much as they need, at a pace and level with which they are most comfortable. When children have unanswered questions or sense secrecy, it can lead to confusion and mistrust.

“Children tend not to be worrying about themselves; they worry about their parents and their siblings; although they might not show it, they will do anything to please, even if it means a lot of extra suffering.”

Sacha Langton-Gilks, in her book *Follow the Child*

These conversations best happen at a time when you feel ready yourself.

Your child's preferences and perspectives are most critical: *Do they want to know? What do they already know? What else do they want to know?*

How Do I Know if My Child Wants to Know?

Has your child asked any of these questions?

- When will I get better?
- Why is my medical treatment different?
- Why am I spending more (or less) time in the hospital?

These questions reflect a deep awareness and curiosity about what is going on in their body.

To remain connected with your child and for them to feel safe and supported, it is important that they are allowed to ask questions. This helps them feel listened to, even if we do not have all the answers. It gives them permission to share their fears and worries.

Very often, children keep quiet to protect their loved ones.

You may also ask your child if they understand what has happened so far. Are they worried about anything? Ask more, tell less. The more openly you communicate, the easier it is for your child who is ready to talk.

“My lovely daughter actually wrote on a piece of paper, ‘Am I dying?’ She couldn’t talk but I could explain to her. I said, ‘Yes, we think you are not going to get better this time and that you will die.’ I couldn’t believe it when she actually wrote back, ‘Thanks for telling me, that’s what I thought too.’”

Mother of a 16-year-old girl¹

What Are Children’s Informational Needs and Patterns of Communication?

Children at different ages have varying understanding of sickness and death, and cope in diverse ways. What is similar, is that all children and young people with serious illness, especially if terminal, will need help to realise that death is a part of life, and to feel supported by loved ones.

It is helpful for parents to be aligned, and agree on key information that they will share with their child. Mixed messages will be confusing and distressing.

“I am going to be a guardian angel and look after my mum. I will always be there to show her that I love her and always will.”

7-year-old girl¹

“I know where I am going, I’m going to God and I’m not going to be in pain anymore.”

14-year-old boy¹

Age Groups	Patterns of Understanding/Behaviour	What Usually Helps
Infants and toddlers aged 0-2 years	<ul style="list-style-type: none"> ▪ They can be affected by the emotional distress of grieving adults around them. ▪ They have no understanding of time or death. 	<ul style="list-style-type: none"> ▪ Providing a sense of security and familiarity. ▪ Being close to caregivers. ▪ Having regular routines.
Pre-school children aged 3-5 years	<ul style="list-style-type: none"> ▪ They may not understand death, or believe death is final. They can get confused between fantasy and reality. ▪ They may have heightened separation anxiety and fluctuate between being needy, withdrawn, sad, and indifferent. ▪ They may demonstrate regressed behaviour e.g. bed wetting, or tantrums. 	<ul style="list-style-type: none"> ▪ Allow the child to share their thoughts and questions about illness and death. Respond with short and simple explanations. ▪ Be more attentive and be generous with physical affection. ▪ Stick to regular routines. ▪ Use play to help make sense of what is going on.
Children aged 6-9 years	<ul style="list-style-type: none"> ▪ They may still have magical thinking and associate death with ghosts and witches, and this could be scary, mysterious, or intriguing for them. ▪ Some may feel guilty or responsible for their predicament. 	<ul style="list-style-type: none"> ▪ Having regular routines, reassurance, and getting simple and honest information are often most helpful.
Children aged 10-12 years	<ul style="list-style-type: none"> ▪ Most children at this age know that everyone dies – that it is final and not reversible. ▪ They may show fluctuating behaviour and emotions. ▪ Some grieve openly, some choose to do it privately. 	<ul style="list-style-type: none"> ▪ Establishing a constant and trusting support network with family, friends and teachers. ▪ Allowing them to talk about their concerns and fears. ▪ It may be helpful for them to use other modalities, (besides talking), to express themselves, such as music, art, or play.
Teen-agers	<ul style="list-style-type: none"> ▪ Adolescents have awareness about death, and they may ask philosophical questions about life and death. ▪ Some grieve openly; some find it easier to be with friends, than with family. ▪ They may act out of character, become more rebellious, more judgemental of themselves, or more withdrawn. 	<ul style="list-style-type: none"> ▪ Respect the young person as an individual. ▪ Seek their thoughts and opinions about their own health. ▪ Allow them some control in making choices where possible. ▪ Parents should strike a balance between providing support, and respecting their space and identity.

If My Child Appears Curious, or Asks Difficult Questions, How Should I Respond?

Stop what you are doing at the time and give them your fullest attention. Be honest. Use simple words and phrases. Some children prefer all the information at once, while some only want a little at a time.

Acknowledge that it is not an easy conversation, but their worries are important to you. Encourage them to ask anything they want.

Give them time to respond to what you have shared. Some may show their responses immediately; some may act as if they did not hear anything.

Do not be afraid to show your own emotions. Crying is cathartic, and can give your child permission to cry too.

These conversations around illness and death are often viewed as taboo. However, once the initial resistance is overcome, it does open the opportunity for very deep conversations.

“My brave, brave son asked me, ‘Am I getting better, ’cos the chemo has been stopped?’ I told him, ‘We have stopped the chemo, because it is not working any more’... A few days later he asked me, ‘Does that mean I could die?’ Together, his mother and I sat down and told him, ‘Yes it does.’ I never want to go through that talk again. I thought I was going to be sick. Again, a few days later he came and asked a bit more. It taught me how he really needed only a tiny bit of information a bit at a time. It made it much easier for all of us, in a sad kind of way.”¹

Father of a 10-year-old boy

“My eight-year-old daughter made a special life box. We talked about and sorted through her favourite pictures. She put in some favourite stones and shells and all kinds of special things she had collected over the years. It became a little ritual to do every day. What goes into her special box? How shall we decorate it? I loved the box and filling it with her was something I will never forget. I may cry when I open it, but we did it together and it’s precious to all of us.”

Mother of an 8-year-old girl¹



What Else Can I Say or Do to Comfort My Child?

Some children may wish to express themselves in non-verbal ways. You can engage in meaningful activities with your child, in the form of writing, artwork, music-making, or going through photographs.

They may sometimes wish to put special things together in a box (e.g. create a “My Precious Things” box) to leave behind for others.

Another useful way is to share with your child your personal experience with others who have been seriously ill. Narration of stories with religious themes can also be helpful and supportive.

A listening ear, or a reassuring hug may sound simple, yet could be most reassuring and comforting at this time. Let them know you will be with them every step of the way.

“Redefining hope is the essence. We all have hopes and dreams and have them for our children, but a devastating diagnosis like this means we have to change them. Facing up to your child’s death does not mean you are giving up. Hope is not being taken away; you are still being positive – it’s just that you are striving for something different to cure. Hope is the expectation of a good that is yet to be.”

Sacha Langton-Gilks, in her book *Follow the Child*

“Even if we cannot hope for life, we hope for our child to have meaning, dignity, comfort, and to enjoy what is left of life.”

Hannah L. Kushnick
Senior Associate Editor, *AMA Journal of Ethics*

Summary

- Take it easy. Do not expect to always get it right. It is okay if your child does not want to talk at the time. It is also okay if you need more time yourself.
- Your child is the expert of their own body, mind, and heart. Their readiness, needs, and preferences are most important.
- If they show curiosity or doubt, offer them opportunities to have these conversations. Be sensitive to their cues. It is okay if you do not have all the answers.
- Seek support from the medical team. Sometimes, it helps for a third-party to be involved in difficult conversations.
- Despite the sadness and grief, these conversations provide opportunities for children and young people to make critical life choices based on what they value.



Communicating with the Siblings

By Dr Chong Poh Heng and Ren Hui

Why Is This Important?

When someone in the family is seriously ill, this affects everyone at home. Routines change, family focus shifts, and a whole array of emotions may be elicited. Children are naturally curious. They are extremely sensitive too. They know when something major has happened. They can tell when their parents look troubled or distracted. Besides, there must be a reason why their brother or sister needs to go to the hospital frequently or stay there for prolonged periods.

- The siblings may worry about what might happen next, or may think they have done something wrong to cause the illness.
- When the parents' attention is focused on the sick child, siblings do feel neglected; this is made worse when they are left under someone else's care as their parents spend hours or days at the hospital.

- They can feel jealous when the sick child gets all the extra attention; some even wish they were sick too!
- The siblings experience significant uncertainty, occasionally coupled with fear, when they do not know what is going on or have many questions unaddressed.

It would be good if someone whom they trust and can communicate with is available for them. Dedicated sibling moments help them feel important and loved. These avenues also allow them to express their feelings or concerns. Studies have shown that their future psychological well-being is associated with how they are engaged and involved at this critical time.

In summary, if the informational and emotional needs of siblings are not met, they can feel confused, jealous or abandoned. They may imagine the worst or sometimes think they are partly to blame. In essence, siblings in the family will not go through the entire experience unaffected. The best thing we can do is to acknowledge and address those emotions, involve them throughout, and not forget to remind them that they are equally loved too.

When to Start Talking and How?

1. When Your Child Is Sick

- Start conversations with the siblings as soon as possible, preferably at the onset of diagnosis of a serious illness.
- Doing relevant activities together are good ways to begin, such as creating a family scrapbook or selecting a “get-well” gift for the sick child. These can trigger delicate conversations in a non-threatening way.
- In the process, explore their understanding about what is happening and if they have questions.
- It is fine if you are not ready to talk about their sibling’s illness. Tell them gently that you will return to them later.

- It is okay to say you don't know or do not always have answers. It is also alright to share your feelings (they are able to observe you), like how worried you are, and that doctors are doing their best to help. At this point, you may want to explore if they have particular fears.

2. As Your Child's Sickness Progresses

- Keep information factual and basic. It is always good to find out how much they already know and ask what they would like you to tell them.
- Be honest, so they are not confused or get resentful when they discover a different reality in the future. The use of familiar stories or analogies that children relate to, such as the book and movie "My Sister's Keeper", or the natural flow of life that comes with the change of seasons, are aids to foster understanding around death and dying.
- They may need reassurance that their sibling's illness will not spread, or has nothing to do with what they might have done in the past. In some cases, siblings may also need to know they will be fine and are not going to die themselves.
- Children often ask the same question many times to process complex information. Stay patient and reply honestly and consistently.

3. After Your Child's Death

- Explain to the siblings what happened as soon as appropriate.
- Share facts in a simple and age-appropriate way to avoid confusion and unnecessary fears. Avoid describing death as "sleeping" or "went to hospital and not coming back".
- Keep the conversation focused on the siblings, while continuing to do the things they love.
- If a child asks to stop or wants to leave, it is likely that they cannot concentrate anymore or cope with the situation. It is perfectly fine. Parents may need to give permission for them to leave or go back to play.

- Do remember that even if a child did not grieve initially, they may ask questions or have changed behaviour at a later date, probably when you least expect it.

Other Than Having a Conversation, What Else?

- Maintain the bond between siblings. When all the attention is given to the sick child, the siblings' relationship can be affected or become worse. Find some activities all the children can do together. Do remember that when the sick child receives a gift, the other children receive theirs too.
- Allow siblings to visit at the hospital when appropriate. It helps them to gain a better understanding about what is going on. It also provides an opportunity for siblings to start asking questions about their sick sibling.
- If the siblings are not allowed in the hospital, encourage them to make a card or draw a picture. You can also ask siblings to choose a favourite toy to be sent to their sick brother or sister in hospital. This gives them a sense of control too.
- Find ways to allow siblings to perform age-appropriate household tasks. However, remember not to rely on them as caregivers before they are ready.
- Have fun together with the siblings. It is okay to play and laugh, and it might be just what you both need – to relieve stress and recharge.
- Set one-on-one time with your other children; not to talk about their sick sibling, but to focus on them and the things going on in their lives.
- Keep usual routines as much as possible, such as school times, meal times and other activities. You may need to seek support from your friends or relatives to achieve that.
- Seek support or therapy from professionals if needed. These could be individual or group-based programmes.

“Children are naturally curious. They are extremely sensitive too. They know when something major has happened. They can tell when their parents look troubled or distracted.”



“Dedicated sibling moments help them feel important and loved. These avenues also allow them to express their feelings or concerns.”

How Might Siblings Respond?

- They may react as if they heard nothing, often a reaction to shock.
- Those who are left guessing find relief when they learn what has actually happened.
- Changes in behaviour may be observed: withdrawal, anger and aggression, just being difficult, or becoming clingy.
- Children often display different sides or feelings to different people.
- Similar to the need for individualised ways to engage the sick child, siblings will respond differently to stressful situations, bad news or even death with respect to their levels of neurocognitive development.

Where Can You Get Help if Needed?

Very likely, you are already receiving support from a palliative care team, whether in the hospital or at home. If not, ask your physician about them.

This group of healthcare providers work in multidisciplinary teams that aim to support all kinds of needs, including those related to helping you manage difficult conversations.

Do not hesitate to reach out and ask for help. They have vast experience in supporting families in challenging situations like the one you are in, and will readily share with you what other families have taught them in the past.

Sources of support:

- Child life specialist or play therapist
- Sibling support programmes (group-based)
- Social worker or counsellor
- Clinical psychologist
- Child's teacher in school

Summary

- Do not leave out the siblings.
- The siblings' feelings matter too.
- Seek help when needed from family and professionals.





Communicating with the Extended Family

By Dr Chong Poh Heng and Ren Hui

Understanding Grandparents' Informational Needs

- Grandparents experience “double grief” when their grandchild turns seriously ill. They not only grieve for their grandchild; they also witness the pain of their own child. This is hard to accept and they can feel both helpless and hopeless.
- When all the attention is given to grieving parents, grandparents may find themselves forgotten. Sometimes, they perceive they are “the last to know” – either because their children are too overwhelmed to update, or they wish to protect the grandparents from hurt.
- Grandparents sometimes feel guilty that they have not spent enough time with the grandchild, or when the grandchild is anticipated to die before them.

- Grandparents concurrently experience changes related to their life stages like retirement, health issues, and death of friends and family members. Impending or risks of death of a dearly loved grandchild may compound their overall grief experience.
- While they could be overwhelmed, grandparents often bring a different perspective from their rich life experiences. They share an appreciation of the mystery of life or insights from their hard-earned wisdom. This brings “comfort to the soul” for everyone involved.
- Some parents have existing intimate relationships with their own parents. During a child’s illness, they find physical and emotional support from their own parents “integral to survival”.
- However, where such warm and supportive relationships do not exist, they might find connecting with grandparents in those instances counterproductive, adding unnecessary burden during an already difficult time. In these situations, it is sometimes helpful to communicate openly, and set clear boundaries to minimise misunderstandings and conflict.

Communicating with the Rest of the Extended Family

- The extended family members (beyond the grandparents) are potentially additional sources of support to parents of a seriously ill child.
- That said, they may unintentionally cause hurt or offence during casual conversations. It is okay to let others know if they have upset you in any way.
- You can be very sensitive at this time. This is absolutely normal. Remember though, that the relatives mostly mean well. Try to see things from their perspective and decide whether to accept whatever assistance or advice is offered.
- Let them know if you do need help, whether in practical things (e.g. helping with childcare), in a physical sense (e.g. a hug), or in an emotional way (e.g. a listening ear). They often feel relieved to be able to help and be useful.

- Provide them with relevant information along the course of the illness where appropriate, perhaps through your spouse or close relations. Their feelings and worries also deserve acknowledgement.
- Particularly within a close-knit family, it is often necessary for the extended family to know what is really happening to the sick child.
- And if unfortunately, when death is expected, offer members of the extended family who also love the child very much a chance to say goodbye.

Summary

- The extended family can be a source of comfort or in some instances, a greater burden.
- Their curiosity and concerns are still valid nonetheless.
- Decide what helps your family and then communicate to them in a clear and timely manner.





Making Difficult Decisions

By Dr Siti Nur Hanim Binte Buang

Over the course of a child's illness, parents make many decisions about their child's care. While every decision is important, some are more challenging than others.

Examples of situations where difficult decisions have to be made include when:

- Your child's health worsens, or a medical crisis occurs;
- The treatment offered is high-risk or has long-term health effects;
- The treatment is no longer working, or causing more harm than benefits;
- No other treatment options are available for your child's condition;
- Deciding whether to limit invasive artificial life-support measures when there is little benefit;
- Whether the medical team should attempt to resuscitate your child if their heart stops beating.

Decision-making is made harder when you are in a state of heightened emotions, which is normal during stressful situations. You may also have limited time to make choices during a medical crisis.

Where to Start

Parents often have to balance many factors in decision-making. You may start by having conversations with the different stakeholders – like your child’s medical team, your spouse, your family and your child. It may be useful to maintain the focus of these conversations towards a common goal, i.e. the best interests of your child.

What is important to achieve in having these conversations is an understanding of:

- What your child’s medical team recommends;
- Your/your family’s values and beliefs;
- What your child wants;
- How your family will be affected.

The medical team will usually continue to engage you in an ongoing conversation to help guide the decision-making process. Sharing your values and preferences for your child will help you and your child’s team reach a shared decision about the care experience you hope for your child.

Shared Decision-Making

Shared decision-making (SDM) is a process where clinicians, patients and/or surrogate decision-makers (like parents, caregivers and family members) share information and take steps to build a consensus or agreement about preferred medical care.¹

¹ Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social science & medicine* (1982), 44(5), 681-692.

The goal of SDM is to facilitate medical decision-making that is aligned with the patient and/or surrogate's preferences, values and goals.

Suggested Framework for Shared Decision-Making

The following points and guiding questions may help provide a framework for your decision-making process. Figure 5.1 illustrates this process which may require multiple discussions with different stakeholders.

While some guiding questions touch on topics that are challenging to many parents and may only be relevant for some, they can act as useful tools to navigate thought processes during acute crises.

You may approach your child's medical team, medical social worker or a member of the palliative care team for help and guidance to think through these tough issues during a critical period or at your own pace in "peaceful" times.

1. Relevant Medical Information

Getting adequate information is critical in understanding what lies ahead. There can be many uncertainties in your journey. Knowing what is the "best" option in care and treatment can be difficult. Every child is different. The response to any treatment may also be difficult to accurately predict.

Gathering and understanding relevant medical information and realistic treatment options from your child's medical team is an essential first step in decision-making. It would also be useful for the medical team to know how much information you would like.



Important information would include:

- The current standard of care for your child's specific illness;
- Possible options for treatment, based on their current health and previous treatments;
- The benefits and harm of treatment;
- Your child's prognosis and what the course of the illness might look like.

Questions to consider:

- *What is the treatment goal?*
- *Is your child expected to get better?*
- *When (and how) will you know whether the treatment is working?*
- *How can you ensure your child's comfort and quality of life during treatment?*

2. Establishing Goals of Care

Discussing and developing goals of care as a family will be helpful in guiding your decision-making process. Goals of care may change over the course of treatment, as your child's disease and/or health condition changes over time.

Goals of care may include more than one of the following:

- Curing the disease;
- Prolonging life;
- Prioritising a good quality of life;
- Keeping your child pain-free and comfortable.

Alternative goals of care that may address the well-being of the rest of your family include:

- Knowing everything possible has been done to care for your child;
- Helping other family members cope with your child's illness and treatment journey.

Questions to consider:

- *As your child's health changes, how does it affect your care goals? Is there a shift in your priorities for your child? What becomes your most important goal, for your child, and for your family?*
- *If your child becomes sicker despite ongoing treatment, how can you balance seeking further treatment options for life prolongation while ensuring comfort and quality of life for your child?*

3. Personal Values, Beliefs and Preferences

Knowing your child's and your family's values, beliefs and preferences will help guide the medical team to make the best plan of care for your child.

Include your child's preferences and values whenever possible. Speaking to your child may require consideration of their understanding based on their mental capacity, maturity and preferences (willingness to participate in this discussion, or otherwise).

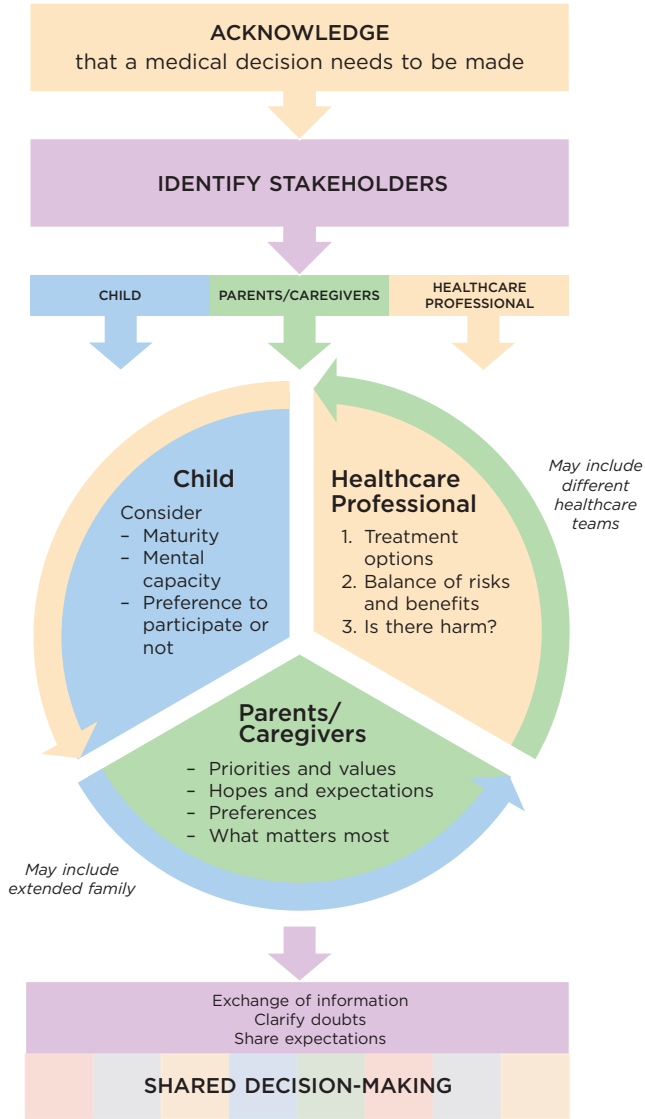


Figure 5.1: Flowchart for Shared Decision-Making

Questions to consider:

- *What are your fears and worries about the future?*
- *Considering both the best and worst case scenarios (given your child's condition), what are your hopes for your child and family in each situation?*
- *Have you considered what specific life conditions or state you (and your child) would find unacceptable for your child to be in? For example, being dependent on artificial life support when there is little chance of recovery.*
- *If it is inevitable that your child is dying, where is your and your child's preferred location for them to spend their last moments?*
- *Is there the possibility of a "good death" for your child, and what would it look like, for you, your family, and your child?*

Summary

- Based on available medical information, explore family values and potential implications of decisions made.
- As circumstances evolve, ask hard questions to fine-tune goals of care throughout your child's illness journey. Hopes and wishes may not remain the same.
- Share your thoughts with your medical team. This allows them to plan the most appropriate management for your child.
- Even while pursuing further treatment, determine what is unacceptable. Think about what a good death may look like, if dying appears inevitable.
- Ask for help if needed, as working through these considerations by yourselves will be difficult.



Legacy Building

By Desmond Tan

What Is Legacy Building?

One's legacy is not simply about what we leave behind or how we are remembered after death.

Legacy building is about creating meaning through the stories we hope to tell. These stories are worth sharing and remembering for years to come, no matter in life or death.

Some parents may associate the introduction of legacy building with giving up hope. They may only consider it when treatment options are exhausted or when their child is near the end of life.

However, one's legacy is underpinned by the universal human experience. Anyone can embark on legacy building; it is not merely for the sick, terminally-ill or deceased. It can only be produced within the context of life, through our lived experiences.

When Is the Right Time for Legacy Building?

Parents have expressed a wide range of preferences over the right time for legacy building, oftentimes subject to their readiness.

As much as possible, it is recommended that the timing should be driven by your child and family.

Please speak to your child's healthcare professionals (e.g., medical social worker) to seek further consultation.

What Are Some Common Forms of Legacy Building?

Legacy building may take on a wide range of different forms and mediums.

It is common for paediatric healthcare facilities to offer the creation of physical legacy items as keepsakes. These may include plaster hand moulds, handprinted artworks, locks of the child's hair, memory books and family portraits. As embodiments of their stories, families and children themselves have found these mementos to be very meaningful.

Children can also take on a more active role in the legacy building experience by participating in living legacy projects or having their wishes fulfilled.

“A time capsule box helps to document my family's memories and values. It includes family photos to remind us about the importance of spending time together as a family. The pictures of my child also remind us of his qualities, like his fighting spirit against his illness. It is a good trait for the siblings to learn.”

Mother of a 4-year-old-boy with 2 siblings

“Sometimes when I am free, I will go through the pictures. The pictures (with the child) capture good memories. It is very nice and can be quite funny. It is therapeutic for me. Over the years, many things will change but pictures will not.”

Grandmother of a 10-year-old boy

These projects may involve collaboration with healthcare professionals and wish-granting bodies. They provide a creative outlet and platform through which children can tell their stories. For instance, stories could be shared through a published autobiography, video and photo journalling, blogging or even song-writing. You can even commence a project as a family if your child already has an idea of what to do!

Get in touch with your child’s healthcare professionals to find out more about the legacy activities offered.

Emily (name has been changed) was diagnosed with congenital heart disease at birth. Since young, she has been an avid painter. After Emily was referred to a paediatric palliative home care service, her nurse and medical social worker discovered her long-held wish of having an art exhibition in her name.

Conversations were held with Emily and her family to find out their preferences. In the process, the home care team came to know of Emily’s desire to contribute to her family and the community, who have showered her with unwavering love and care over the years. In addition, they preferred an exclusive event, to be attended by people close to Emily’s heart: extended family members, friends and healthcare professionals involved in her care.

Emily auctioned her artworks through the exhibition to generate some income for her family and donate part of the proceeds to charity as a way of giving back. The art exhibition also presented an opportunity for loved ones to own one of her artworks. In preparation, Emily penned the stories behind each artwork, detailing her reflections, love and gratitude for the people and things in her life.

Alongside the team and a group of volunteers, Emily's parents and older sibling were deeply involved in the planning and execution of the event. It received rousing support from the attendees. A photo booth (with Emily's favourite film, "Frozen", as a backdrop) was set up and a volunteer photographer was present to help commemorate the occasion.

An example of a simple legacy building activity for your family to do:

Family collage: Choose pictures from magazines or use family photos to create a family collage together. This item represents memories and stories of the family as a social unit.

Materials: Canvas board/drawing paper, family photos, old magazines, scissors, glue, coloured pens, paint, and stickers.

Steps:

1. Family members select and cut out photos or magazine pictures that they would like to add to the family collage.
2. Glue photos/pictures onto the canvas board/drawing paper.
3. Decorate the collage with quotes and drawings using coloured pens, paint and other materials.
4. Use the collage to share a memorable story about each family member and the family as a whole.

“My child’s hand mould is precious to me because it affirms his life and proves that he exists. When I hold it close, I can see the tiny details and fine lines on his hand. It makes me feel warm and as if he is here with me.”

Mother of a 2-week-old baby boy

How Does Legacy Building Benefit My Child and Family?

Studies have shown that legacy building can help children with a life-threatening illness and their families cultivate mental resilience as they struggle to make sense of their experiences.

Legacy building can help your child cope by promoting a sense of normalcy and achievement through activities like art-making. Storytelling allows room for self-expression and encourages meaning-making. These activities can also fight boredom and serve as a distraction from the hospital experience.

Parents of children who have participated in legacy building activities reported positive experiences. They allow for further exploration of their child’s feelings and worries, allowing parents the opportunity to address these concerns. This promotes communication and helps strengthen their relationship with the child. Siblings and other loved ones may benefit when they are involved in this process too.

Legacy building can also bring comfort to your child near the end of life, as many children need and want to know that they will not be forgotten.

Parents worry about losing memories of their child too. They often describe the preservation of their child’s legacy as an essential aspect of coping and meaning-making in bereavement. For instance, a physical memento may provide a tangible connection and support continuing bonds between parents and their child.

Where Can I Seek Help to Fulfil My Child's Wish?

Children's Cancer Foundation (CCF)

Their Wishlink Programme offers wish granting to children. Get in touch with your child's CCF Social Worker to find out more.

Make-A-Wish Singapore

Make-A-Wish Singapore is the local arm of an international children's charity that grants the wishes of children aged 3 to 18 years old with critical illnesses.

Referrals are accepted from healthcare professionals, parents/guardians or even the children themselves through the Make-A-Wish Singapore website. Speak to your child's healthcare professionals if you need assistance to make a referral.

Others

Many other healthcare organisations and services may offer wish granting services. Please get in touch with your child's healthcare professionals to find out more.

Organ Donation

Finally, there is yet another form of legacy making that some parents and even children and young people with serious illness can consider. Corneas and other organ parts where appropriate have been pledged and gifted. This has led to meaningful closure and tremendous comfort for certain families.

Consult your healthcare team for more information if this ever crosses your mind or is perceived to fit your needs as a family. They will be able to advise on individual suitability and administrative processes.

Summary

- Legacy building is a way for children and families in this situation to find meaning.
- It can happen any time after the diagnosis of a serious illness, not just when one is dying.
- The right time and form it takes depends on each child and family.
- Greater resilience and better coping are intrinsic benefits. Communication and connections are also strengthened in the process.
- Organ donation is another way for enduring legacy making that some families have found most rewarding and healing.



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About Singapore Hospice Council



Established in 1995, Singapore Hospice Council (SHC) is a registered charity and an Institution of a Public Character (IPC). We are an umbrella body representing organisations that actively provide hospice and palliative care in Singapore.

SHC is committed to improving the lives of patients with serious life-limiting illnesses and to giving support to the loved ones of these patients.

www.singaporehospice.org.sg

About the Contributors

Dr Chong Poh Heng

Dr Chong Poh Heng is the medical director of HCA Hospice and founder of Star PALS (Paediatric Advanced Life Support). He chairs and participates in several advocacy efforts such as the paediatric and young adults Advance Care Planning (ACP) task force and the Asia Pacific Hospice and Palliative Care Network (APHN) Paediatric Palliative Care Special Interest Group. Dr Chong was also awarded the Healthcare Humanity Award in 2015 and the President's Volunteerism & Philanthropy Award, Leader of Good Award in 2021.

Ren Hui

Nurse Manager Ren Hui has been with HCA Hospice as a Star PALS Nurse since 2014. Throughout her tenure, she has been deeply committed to tending to the needs of her patients and their caregivers. Ren Hui's extensive interactions with families during home visits have afforded her deep understanding of the myriad challenges they face, allowing her to provide not only medical care but also empathetic support that truly makes a difference.

Victoria Ng

Victoria Ng is a practising Registered Art Therapist (Art Therapy Association Singapore) at the Department of Paediatrics at the National University Hospital (NUH). Using art as a tool for healing and self-expression, she specialises in providing palliative and bereavement support for children and adolescents coping with chronic illnesses. Having witnessed the benefits of art therapy through her work, Victoria's passion is in helping clients bridge language and emotional barriers through creativity, and providing a safe space for emotional exploration, growth and resilience.

Dr Siti Nur Hanim Binte Buang

Dr Siti trained and worked as a paediatric intensivist in KK Women's and Children's Hospital (KKH) for 10 years before embarking on further training in Palliative Care. She is now a Consultant in Paediatric Palliative Care in KKH. She is also the clinical lead representing Paediatric Palliative Care Service in the SingHealth Duke-NUS Supportive & Palliative Care Centre. She has been awarded the SingHealth Doctors and Dentists Long Service Award in 2015 for her continuous dedication to patient care.

Desmond Tan

Desmond has been a Medical Social Worker in the Star PALS (Paediatric Advanced Life Support) programme at HCA Hospice since 2016. Desmond works closely with families and supports them through arduous journeys that challenge them in so many ways - by being there for them during difficult times and helping the patient and family live well.

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Dr Teresa Tan is a Consultant in Paediatrics and Palliative Care at the Khoo Teck Puat - National University Children's Medical Institute (KTP-NUCMI) at the National University Hospital (NUH). She received the FY2022 Learning Development Award for a clinical fellowship with the Queensland Children's Hospital Paediatric Palliative Care Service. She has also contributed to the Singapore Paediatric and Young Adults Advance Care Planning task force and the KTP-NUCMI Paediatrics Ethics and Advocacy Centre workgroup.

Notes

When a Child *Has* Serious Illness

When a child has serious illness, for any parent, coming face to face with the possibility of losing them can be an unfathomable and heart-wrenching experience.

*What should I say to my child?
How can I comfort my child in pain?
Which is the best decision for my family?*

These are some of the most profound yet necessary, important questions.

Unquestionably, no parents are ever prepared for a child's death. This guide, *When a Child Has Serious Illness*, has been put together by an expert panel of medical professionals to offer insights and practical advice to help parents navigate the host of challenges. These include supporting a sick child, making difficult decisions, communicating with family, and finding ways to remember them. It is hoped that the guide serves as a source of comfort for parents and reminds them that they are not alone in this journey.

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