Making
hard decisions
about care

Introduction

You are reading this because someone on the team of people caring for your child has a brave heart. He or she, or it may even be you, has faced the painful fact that despite the best efforts of medicine, and the deep love and support of your family, your child may die.

You are reading this because though you maintain hope – and hope is powerful – you want your hope to be wise, not foolish.

You are reading this because you want the best for your child – the best life possible and the best death possible. While we do not have control over birth or death, there is much that we can control. We express that control in the choices we make. You need to be prepared to make good choices for your child whatever lies ahead. This book is our attempt to help you prepare yourself.

We hope you will find much of value in these pages. All families work out their own ways of being and coping. We do not expect that all our suggestions will fit for your situation. Take what is helpful, adapt when you can, and discard what is not useful for your family. There is no one right way to move ahead. You will need courage and support. We hope you will find the first within yourself and the second, among your family, friends and the health care team.

Editor's note:
To keep sentences simple, I will use either "he" or "she; "his" or "her"; "son" or "daughter". In your head, please change what is on the page to the correct form for your child.

This pamphlet is the result of a
collaboration between
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and Canuck Place Children's Hospice

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CANUCK PLACE
CHILDREN'S HOSPICE

Treatment choices about the approach to care

When a parent hears "*This treatment is not working … we've tried everything we have here…*" or "*This new crisis is really a turning point, we must think hard about how we respond …*" the words can strike like a thunderbolt and feel like a powerful punch in the gut.

These words signal that you are arriving at a major decision point - you are being asked to decide on the best plan for your child's care. You will be asked to answer some of the toughest questions life can ask. You are right – it isn't fair.

A time is coming when you will be asked to accept that there is little possibility for a cure, or even a return to the level of health that your child has had in the past few months. In the case of a child with a degenerative condition, the time might present as another medical crisis to which you must respond. You may be told that there is a short time left in your child's life. The others on your child's team will want guidance about how you want the rest of your child's life to be lived. This choice is between shifting your focus of care to **palliative treatment** or keeping the focus on **active treatment to slow the progression.**

Decisions that you make with head and heart working together are surely better than those made with just head or just heart

Is the <u>first</u> goal of treatment going to be quality of life rather than length of life? Choosing one does not always mean giving up on the other.

Two approaches to care

Active treatment uses whatever medical science knows to keep death at bay. What the body cannot do for itself, science and technology supplies.

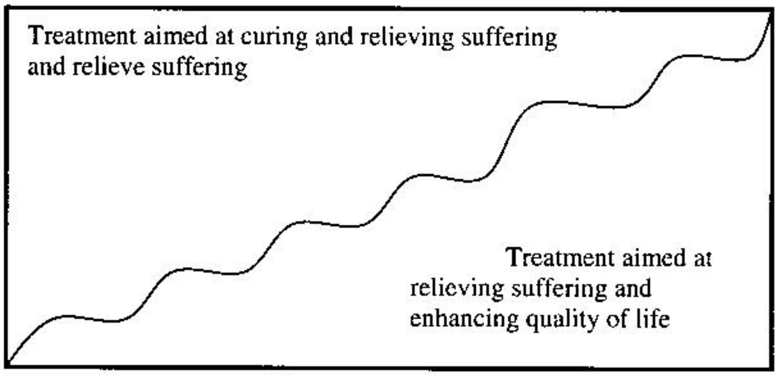
Palliative care regards dying as a normal process that care neither speeds nor delays. Health professionals focus their expertise on symptom relief rather than cure. Palliative care offers a support network to care for the whole person and those who are sharing the person's end of life.

Quality of life is always important. If the goal is cure, however, some unpleasant side effects are tolerated for long term benefits.

Although palliative care will include buying time for the person, it will not be at the expense of comfort and well being here and now.

Thinking ahead and choosing "the path that will ease the journey"

A choice of the type of care you want for your child is never really a choice of either one or the other. It is more a choice of where you want the main focus to be at any point. Think about moving on a road that cuts across a rectangle of care.



At one corner on the road the care plan involves almost 100% focus on active treatment. At the opposite corner almost 100% of the focus is palliative care. At any other point on the road there is some of both happening. Think about this decision as stepping out of the corner. You will then see that your child's care plan will include both kinds of care that will adapt to changes in your child's condition.

No one can ever be fully prepared for these decisions. Some ways of starting to think through this kind of decision are listed below.

Be clear about the kind of decision you are making

It is important to think about the decision you are going to make so that you take responsibility only for what you can control. Neither you, nor the rest of the health care team, can give or take the life from your child. No one has that power. You are not making a choice about giving up on life. You are deciding only how your child lives the life he has now. Should the main focus be on comfort rather than on trying for longer life?

You will not be making the decisions alone. The health care team will make them with you.

Remember these things:

- Whatever decision you make, you will continue to hope and even wish for a miracle. Wishes and miracles do not depend on treatments or decisions.
- Whatever you do, is done out of love for your precious child. Your child feels that love.

Gather good information

Ask questions and, if you need to, do your own research. To be at peace with your decision, both now and in the future, you must be as sure as you can that you have tried everything **worth** trying. Everything that is worth trying is not the same as everything there is to try.

Some questions you may want to ask your child's care team:

- *How can you be sure that what you are doing isn't helping …..?*
- *Is there any chance that we will see an improvement?*
- *Have you ever tried continuing the treatment plan beyond this point? What is the chance that it might work this time?*
- *Is there anything, anywhere other than here, that might give … a chance?*
- *What is wrong with trying something more just in case it helps?*
- *Is there anything that will give us more time?*
- *Can we do some part of the plan and not another?*

It is helpful to write down what you learn. You can then refer to these notes when you review which options seem worthwhile and why. Be aware that the doctors may not always accept the family's views on the medical treatments worth trying. They may not be willing to give treatments against their best professional judgement.

Consider whether there are others, not part of the health team, with whom you want to discuss your thoughts?

Try talking to other parents, family or a spiritual leader.

Keep in mind that others may offer opinions of what they would do. They are not you. Their opinions may or may not be supportive.

Look inside yourself for your beliefs about quality of life

Up to now you may have thought very little about what "quality of life" means for you. You may not even be sure that you and your partner share the same values about quality of life. It will be very helpful if you can be as clear and specific as possible about what you mean by quality of life. Some parents have found it helpful to make their own list of what gives "quality" to life, and then compare their lists. Others have found it best to make a list together. If you are a single parent, you may want to ask a friend or a member of staff to help you with this task. Reflect on your beliefs and life values. Try to define what "quality of life" means in concrete terms. Sharing your values and beliefs helps the care team support you. It also helps you understand the "gut feelings" on which you rely.

Some ideas about quality of life include:

independence;
ability to enjoy friends;
basic life activities like eating, moving;
joy in favoured activities;
shared laughter and tears;
being an active part of …;
having the possibility to develop oneself
freedom from pain;
interest in learning;
futility/hope.

Consider what suffering means to you

"I don't want my child to suffer." Almost every parent says that at some point. Or, "she has suffered enough." Most of us use the word "suffer" without thinking too much about what it is we mean by this difficult idea. An important part of thinking about quality of life is really coming to understand what it is that suffering means for you.

Take account of your child's views

If your child is old enough, talk with him about what he values in life.

Listen to your child's wants and wishes. *"I don't want anymore pokes."* Take them seriously.

Evaluate what you know (facts), feel (emotions), and believe (values) about each care option

This may lead you to the best decision.

Commit to your choice. Say out loud:

"I/we choose this for my child …
I/we decide this because …"

In the weeks, months and years ahead you may want to revisit your decision. Spelling things out for yourself in this way takes away some of the confusion and the endless "whys". You can be kinder to yourself if you remember how carefully you made choices for the child you love.

Some ways to think about suffering:
My worst fear is ….
I can deal with most things except …
I'm not prepared to allow …

You can introduce this topic with something like this:

"What has been the best day you can remember having?

"What made that day special?"

"What do you miss most?"

"What is a good part of today?"

> *"At 15 life had taught me undeniably that surrender, in its place, was as honourable as …"* –
> Maya Angelou
> quoted in Help for the hard times by Earl Hipp,
> Hazelden Press, 1995

Choices of the place for care

Where the care takes place depends on:

1. the child's condition
2. the needs he will have in the future
3. the services that are available
4. your family and other personal support networks
5. concerns about people or finances or other things that take away from peace of mind
6. your child's preference
7. and the choices you make.

A good place to start is by finding out as much as you can about the options available to you.

B.C.'s Children's Hospital is mainly an acute care hospital. It can provide active, curative or palliative care although it is better able to provide active care. Because of the pressure on its services, the hospital cannot always provide all levels of care.

A hospice setting like **Canuck Place Children's Hospice** or a **hospice unit in some community hospitals**, is designed to provide the best possible end of life care. This type of care is the specialty of the health care providers who work in this setting. They are able to give professional health care in a place that feels more like a living space than a hospital.

Many families want more than anything to be at **home**. They believe that this is the setting most familiar and comforting for the child. This option is often possible. It needs planning because each person's needs are different. It takes time to put home care services in place. Families sometimes know that this is the care choice they will make but feel it is "too soon" to begin planning. But a better approach is to have a plan in place and services lined up ahead of a crisis.

Parent voice:

Once we had Ravi home we settled into routine that worked well. We all just loved being home. Then he started having so many more seizures and vomiting the tube feeds. It was hard to know what to do. Our doctor suggested we think about going into a hospice. It was a very difficult choice for us – perhaps our most difficult – and that is saying something! We agreed only because we saw no other way to get some quality back into Ravi's life. Once there, we got all the sensitive, professional support we needed. We expected that. But we didn't realise how much comfort we got from being able to talk with other parents about our scary thoughts. Our other kids came with us, and they were able to be with other children who understood what it was like to have a sick sibling. We were now part of a community of people who truly understood. Hospice proved a blessing.

Care at home - thinking it through

The goal of care is comfort and peace – can we achieve this at home?

Things to consider:

- Do we have space, or, can we make space, so our child can have a separate bedroom?
- Can the pain and other symptoms be managed at home – do they require 24 hour care, availability of specialized drugs or equipment – can we get what we will need?
- What help do we need to manage daily physical care like toiletting, bathing, hair washing?
- What health care services are available in the event of a sudden change in the child's condition?
- Is there support from capable and willing health professionals?
- Is there practical help and relief with chores?
- Is there emotional support from meaningful others for us?
- How will this affect the other children in the family?

Services to support a family caring for a seriously ill child at home

If you decide to take your child home, you will need some support. Even the strongest families need support to care for their children. The kind and amount of support will be different for each family. It will depend on the changing physical and emotional needs of their child. It will also depend on the strengths of their family supports and the preferences of family members. But needs and choices may have to take into account what is available in your home community.

> Parent voice:
> *As Jonah became sicker and weaker, we needed more and more help with the care. Every time we asked for help there was another referral and another health professional needing to ask another – or the same – set of questions. Nothing happened without an assessment. There were so many people involved in the care. It became difficult to keep track of things. I realised I had to ask who was keeping track of the overall picture. Another family I knew asked for a team meeting to get everyone on the same page, but we lived out of town. That was difficult to arrange. So, I asked my home care nurse to set up a conference call. I think that helped us all sort out our responsibilities.*

If you consider the home option, someone on your child's health care team will help you work through these questions and put community supports in place where possible. You will not be left alone to do this.

It helps to know that the provincial <u>At Home Program</u> covers many of the costs of caring for your child at home. It will also provide some hours of respite care. The social worker can explain more of this to you.

The needs and choices of the family may change as time passes or as you see what the care involves. What is set up for the first few weeks can be modified later.

Here is a summary of the services that may be available to your child and family. You may already have used some of these.

Nursing Support Services (NSS)

This is a province wide program available in most communities.

- Managed by Ministry for Children and Family Development
- Brings together several programs such as *In School Support*, *Nursing Respite Program, Supported Child Care* and *At Home Program*
- Family needs to be referred to NSS by a health care professional.
- A NSS co-ordinator meets with parents and child (often in their home) to discuss care needs.

  NSS offers:

  - Direct Nursing Care – may be available to provide care in your home if your child needs the judgement and skill of a nurse. The number of nursing hours is based on the child's needs, up to a maximum of 56 hours per week. The NSS co-ordinator will meet with you to assess your child's needs.

    Note: Be aware that there may not always be nurses available when you want them. The NSS co-ordinator will work with you to try to meet your needs.
  - Delegated Care – may be available if your child needs special health care procedures while at school or daycare that a trained caregiver can provide. NSS will train, certify and supervise these caregivers.
  - At Home Program – may be available if your child has severe disabilities or is receiving palliative care. The program covers some of these costs if they have funding:
    - Medical equipment and supplies, transport to medical care, MSP and some prescription Pharmacare (medications), dental and eye care and a few other types of treatment and therapy.
    - Respite funds. Money is paid directly to parents to hire the kind of help they need to give them some time for rest.

Parent voice:
My child needed suctioning often and medications every few hours. They gave us 16 hrs of direct nursing care a week. We chose to use 8 hours, 2 times a week for overnight care. That way my husband and I had a good sleep. As time went on, this just wasn't enough. We were worn out and starting to fall apart more and more so I called the NSS co-ordinator and asked her to come back and review the situation. The service added an extra 12 hours which really helped.

Home Care Nursing

This is a service available in most communities.

- Managed by the regional health authorities.
- Your family needs to be referred by a health care professional.

Home care nurses offer:

- Home visits for nursing tasks like dressing changes or injections.
- Home visits to help caregivers manage symptoms.
- Links among other involved in the child's care eg.occupational / physiotherapists, homemakers.

BC Palliative Care Benefits Program

- This program is available to all children in the province.
- Your family needs to be referred by a physician.

The BC Palliative Care Benefits Program provides money for equipment, supplies and medications, including over the counter medications, which the At Home program does not.

Home Oxygen

- If a physician agrees that a child needs oxygen at home, the Ministry of Health provides it.
- After a referral, a respiratory therapist (if one is available in your community) comes to your home to assess your child's needs.
- Oxygen and supplies are delivered.

Family doctor/pediatrician

A family doctor or pediatrician who can oversee your child's medical needs at home is a key support. You need a doctor who is

- available to your child
- understands the care and the choices your family has made.

When choosing the doctor ask about and consider:

- Can we get to the office/ clinic easily?
- Are the clinic hours convenient?
- Will she do home visits when my child does not have the energy to leave the house?
- Will he accept telephone calls if I have urgent questions about symptoms?
- Does she seem like someone who will understand our wishes and respect our goals for our child?
- Does he seem open to consulting with my child's team of specialists so that I know we will get the best possible care?

Parent voice:
When we first got home, Ryan was doing OK. We knew he was going to get sicker but he did so well for much longer than we expected. The home care nurse checked-in once a week to see how we were managing. It was reassuring to have this visit. Later, when he started to have more pain and more difficulty breathing, she came every day and helped us figure out what to do. She was a great support and a great listener.

Parent voice:
Terror struck my heart when we had to transfer to a different doctor when we went home. We had so much trust in the hospital team. It felt like no one else could give the same quality of care. But, you know, I believe we had the same wonderful care from our community doctor. He told me that at first he was also anxious about taking Sarah as a patient. He knew how sick she was. Thankfully he agreed. He took time to get to know Sarah's history. He went through all the reports from the Hospital. There were many calls back and forth with the consultants. I was touched by his really listening to our stories. We quickly felt confident that he could, and would, do what was needed. And so it was. He really understood our focus and helped us keep Sarah comfortable so she could enjoy her days.

If you need help finding a doctor in your community, ask for a referral from your hospital/hospice team. Make contact with him before you arrive home. The more he knows about your family the better.

Community Palliative Care Teams

Many communities have a palliative care team. These are specialists (often a nurse, doctor, social worker) in treating people in the last months of their life. Health professionals from the team may visit your child and family or support your child's care through your family doctor/pediatrician.

Hospices

Hospice care can offer:

- Rest time for the family to "refuel" before taking on the home care again.
- Help with managing symptoms so the family can cope better at home.
- Support when death is very near and the family prefers to be where medical help is available but does not want a hospital setting.

Most hospices in British Columbia, other than Canuck Place, do not admit children younger than 17 years. But with support from Children's Hospital or Canuck Place, many community hospitals will give hospice-like care in a private room in their pediatric area.

Combining care:

Choosing a place of care does not tie you to that decision. Hospice may be a short term choice that serves as a comfortable place between hospital and home. It can be a place that provides a rest time for you if care at home becomes too stressful for the family. If your child needs special care of some sort, she may return to hospital for a short or longer stay. What you decide may work well for your child and family for many months, or may need to be reviewed after a few weeks.

Before you decide on the place of care for your child, we suggest you hear from each person in the family whose life will be affected. If you have an extended family or other children, old enough to understand, you may want to have a family conference to talk about it. Be aware that your other children may have fears and concerns about your sick child and/or death. This is the time to listen to these.

If the decision to have your child come home (or not) is made by the whole family, then you can expect more help and support from everyone.

Parent voice: *We all wanted to have Rodin at home. The health care team at Children's Hospital set up services and supports. We had such a good first month all at home together. Everyone pitched in and helped. Then Rodin began to have pain and we just couldn't manage it well enough. I was up, and she was up, almost every night. It was exam time and my eldest child could not keep focussed on her studies. We all talked and decided that we needed to get things sorted out with the pain and give Helen a chance to study. I called the community nurse and she arranged for us to go into hospice. I can tell you this wasn't an easy decision but was it ever a good one! They got the pain controlled in the course of a few days. I got some sleep so I could think again. Best of all, we realised that hospice is not at all the gloomy place of despair we had imagined. We went back home for a few more weeks. When the crisis came in the form of a bowel blockage, we went by ambulance back to Children's Hospital. They did what they could to make her comfortable. We all knew home was no longer an option. We chose to spend our last few days together as a family in the hospice setting. We were familiar with it and the people there. We didn't think about it as a place to die, but a place we could be as a family, taking the most from the precious time we had.*