SCCS SERVICES

SCCS is there for you and your family during the palliative care period and beyond. Services include:

Counseling: Our social worker is always there to talk and listen.

Crafts and art projects: The SCCS tutor can work with you and your child to create scrapbooks, memory collages, or other projects.

Home visits: If your child moves back home, we'll make arrangements to visit and see how you and your family are doing.

Parent-parent support network: We can connect you to other parents who have gone through a similar experience and would like to provide emotional support during this time.

Our wish program: SCCS can help to fulfill one of your child's wishes.

Financial assistance: For those in need, SCCS can provide limited funds to meet some of the palliative care needs of your child.

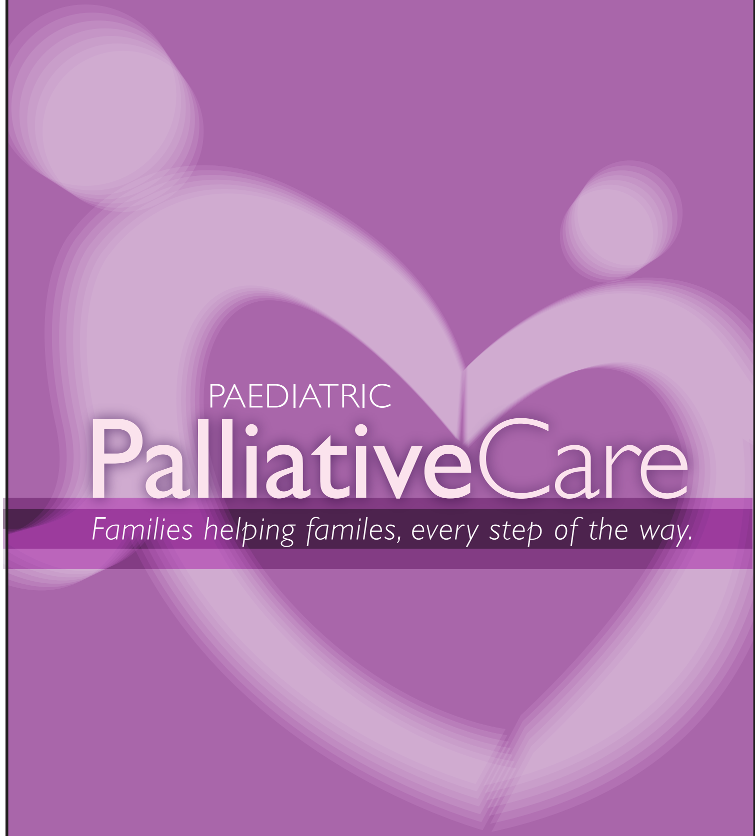
After the passing of a child, SCCS offers support to grieving families. Through home visits, regional family gatherings, and an annual memorial day, we walk with families on their journey, every step of the way.

For more information:

Talk to our SCCS social worker about how to access these resources.

Check out the following books and websites:
"Journeys: Palliative Care for Children and Teenagers"
"Facing the death of your child"
"CureSearch"
www.curesearch.org/PalliativeCare

SARAWAK CHILDREN'S CANCER SOCIETY
(SP 1485)
Lot 5493, Lorong 15, Taman Desa Wira,
Jalan Batu Kawa, 93250 Kuching, Sarawak, Malaysia.
T: 082-686276 F:082-686376
E: admistrator@sccs.org.my
www.sccs.org.my



PAEDIATRIC
PalliativeCare

Families helping familes, every step of the way.

THE SCCS PARENT PACK

Produced by
Sarawak Children's Cancer Society

PAEDIATRIC PALLIATIVE CARE is for children who have a life-limiting illness that is expected to result in a shortened life.

Palliative care aims to maximize quality of life. Palliative care is about the whole person. Palliative care minimizes pain and controls symptoms, but it also has a non-medical component – emotional, spiritual, and logistical support. That's why palliative care teams include nurses, doctors, social workers, spiritual leaders, volunteers, and more.

Palliative care does not necessarily make death come sooner or later - it just makes your child's life better. During the palliative care period, everyone works together to help your child live as actively as she can for as long as she can.

What rights do I have as the parent?

Families can feel overwhelmed, remember:

- You have the right to be informed. Ask questions if something is confusing!
- You have the right to be involved in decision-making at all stages.
- You have the right to receive care that respects your family's religious and cultural background.
- You have the right to confidentiality. Your privacy should always be respected, and medical information should be given only to those who need it to care for your child.

Where does palliative care take place?

Depending on your child's condition, palliative care can be provided in a number of different places – the hospital or even your own home.

Does palliative care mean my child will no longer receive medical care?

No; doctors and nurses will continue to take care of your child during this time.

Depending on your child's situation, your child may continue to take medicine or even get chemotherapy. The difference is that the goal of these treatments is not to cure but make your child more comfortable.

Does palliative care mean there's no more hope?

No one can know what will happen in the future. When your physician talks to you about end-of-life care for your child, she is not trying to "play God." She is just trying to prepare you for what will eventually happen, and to make sure that your child lives the best life possible.

Many parents have difficulty accepting their child's condition. They may still hold onto hope for a cure, even when they know that it is not likely. That is normal. It is okay to hope for the best, but only if you also prepare for other outcomes.

Even if you cannot hope for a cure, there are other things to hope for - making good memories with your child or helping her to be comfortable and at peace.

What should I ask the doctor?

Palliative care can be confusing for a lot of families and is different for each child, so it's very important that you talk with your doctor about what palliative care will be like for your child. Have regular conversations with your healthcare team during this time – they will support you.

Some questions you can ask:

- What are we doing to keep my child comfortable?
- What can I expect as my child's disease progress?
- Will my child be in pain?
- How will we manage it?
- What other symptoms might my child have?
- Can I take my child home?
- If I take my child home, will he receive medical attention?
- If there's an emergency – what should I do?

Can I try complementary treatments during this time?

Most doctors will allow complementary treatments if parents insist, eg herbs, massage and aromatherapy but remember that they have no scientific proof. If they guarantee a cure, you should be skeptical. Be careful about the costs of these treatments; they can be quite expensive, and may not have many benefits.

No matter what you decide, keep your doctor informed. Some alternative treatments cause negative effects or even death when mixed with other medications.

What do I tell my child?

Some parents don't know what to say; some parents are afraid of saying anything at all. Whether or not you want to tell your child that they may be dying is your decision but many families find that there are many benefits to talking with their children about death and dying. For instance:

- Being open with their children draws them closer to each other.
- Children can ask questions and share their fears.
- Children and parents can talk about how they want to spend their time together.
- Children can take care of any unfinished business; eg, say goodbye to friends, give their favorite toys away, or visit relatives they don't always get to see.
- Informed children will understand what's happening. Otherwise, they may try to guess about their condition, and might imagine something much more frightening and painful than the reality.

Some parents fear that telling their child will cause him or her to lose the will to live. However, many families find that when children know they have limited time, they often choose to live life to the fullest.

Doctors, nurses, and social workers can help you think about what you might want to say to your child. We can also provide you with a palliative care picture book that you can read with your child.

Many parents find it helpful to tell their children early instead of waiting for their condition to become more serious. That way, parents and children can still plan fun activities before the child becomes too ill. Keep siblings updated, too.

Some tips on talking to your child

- *Keep it simple and honest.*
- *Hearing from you first is better than letting them find out accidentally.*
- *Answer their questions.*
- *Make sure they understand that their illness is not their fault.*
- *Some families feel that it's easier to have this conversation while engaging in an activity together. This allows for pauses in the conversation, giving the child more time to think and come up with questions.*

NOTES

How can I prepare my child and myself?

Even though it is a very challenging time, it is also a very special time for families.

It's a chance for children to think about what would make them happy, and a time for parents to create lasting memories. Talk with your child about what's important to him or her and do it. Parents and children can create memory collages, scrapbooking, and other art projects together. However you choose to spend your time together, your child will treasure your attention and affection.

How can I cope?

When you're looking after your child, it's easy to neglect your own needs. But remember; if you don't take care of yourself, then it's very difficult to take care of others. Some tips to stay healthy during this time:

- Maintain relationships with the friends you've made at the hospital; - nurse, other parents who have been through similar experiences. and SCCS social worker
- Accept help from others.
- Get enough sleep, and eat regularly.
- Make time for each other. Many couples experience relationship strain during this time; open communication and patience can be helpful.