

ACP Talking Series...

Young children diagnosed with cancer

This support leaflet is for parents/carers of infants between the ages of 0-3 years old who have been diagnosed with cancer. Parents may also find this leaflet helpful more generally in understanding a child who has a serious illness.

Feelings and talking

When your baby is diagnosed with cancer most families want to protect them from the news. Perhaps the last thing on your mind is how to talk about it with them. This leaflet aims to offer you support in thinking about this but also offers suggestions of how talking can help.

You may be feeling overwhelmed by your own different thoughts and feelings. You may feel why would your baby need to know what is happening and what could they possibly understand? Perhaps the burden is heavy enough for you to carry and you feel that your world has been turned upside down. You know you will need to find a way through this very upsetting time and help your little one manage the treatment and experience of being seriously ill.

This leaflet aims to help you find a way of communicating to your baby in a simple way about what that is happening and why things have changed. It will help your baby feel safe. Your CNS, key worker, Clic Sargent Social worker or the psychology service in the hospital *where your child is being treated* are there to support you in doing this for your baby but are also there to support you.

Why does talking help?

Your baby's mind is developing and changing even from the time that they were in the womb.

Your baby will have got to know you even then, hearing your voices or those of their brothers and sisters if they have them. They will respond to familiar music sometimes that of a regularly watched TV programme.

Babies are clever

When they are born babies are ready to meet a human face. Within six weeks babies can even recognise their mother's own particular language. Babies are taking in the world from the moment they are born though sensations, sounds and sights.

What you do

You are helping your baby all the time using your voice to steady them when they are hungry or distressed, talking, nodding and smiling when they are alert and responding, beginning to smile. This is the way they learn about the world and begin to have an understanding of how it works: *when I am hungry I get fed, if I cry someone will come, when I reach out I can feel softness or the hardness of my cot and so on.*

Babies look to their parents to help them manage the world and all that they encounter. You are the ones that he or she will automatically turn to when something is not quite right. When a baby is unwell they will really only want their parents – or their most significant carer/attachment figure/s. This can be hard on you as parents and carers.

Babies are aware


From the time your baby was born he or she will have been aware of changes in the household. Perhaps you have noticed how when you have done something differently, your baby notices and shows you that they have noticed. This is because they are trying to manage the changes, which to us seem small but to a baby for whom the world is new, can feel big and hard to understand. Change can cause fear because they are not yet familiar with their new surroundings and people around them. They need you to help them process everything, to put their experiences into words even if it is only the tone of your voice that they are reassured by.

As your baby grows and develops his or her responses will become increasingly complex, subtle and sophisticated. A baby of about eight months or more may suddenly become more cautious about who he or she goes to.

You may have returned to work when the baby was a year old or younger and because of a baby's highly tuned sensitivity you may have noticed how the baby has responded to this - perhaps their routine and yours has had to change and adapt. This is not a bad thing but it can take a little while for you all to feel settled again.

It helps to talk

It can help if you can talk to your baby about these changes because it enables you all to process it at the same time.



Talking to babies is very important as you are establishing your relationship with them, helping them to communicate but also letting them know that their early attempts to communicate are being responded to as well.

What changes when your baby becomes ill?

Most people feel that their world has turned upside down when their baby becomes seriously ill.

We are here to support you if you wish during this journey. This journey is of course like no other you will have experienced and of course your baby needs you above everything.

You may find that telling your baby, speaking to them about all the changes, may help him or her to cope better with what has happened. This might seem extraordinary that one so young can be helped by talking. It may also help you and your partner, or those closest to you talk together about what is happening.

An expert observer

Your baby will be looking at you and will recognise your stress however hard you try to hide it.

Your baby knows you better than anyone else and he or she will be an expert observer of your facial expressions but also reading how you feel.

This is normal not at all harmful. It is normal and important to your baby's development.

What can you say?

Talking to your baby will help them feel more settled. The tone of your voice is known so well by your baby that it will be reassuring in the same way that it is when they have a tummy ache or are ill in an ordinary way.

It is helpful for everyone to hear the truth. Your baby does not need the detail of their illness of course just straightforward honest explanations about what is happening. This will help to build trust and resilience.

Use your words

It is important that you choose your own family words or words that are familiar for example:-

‘You have a “hurty” (however you name it when they are unwell) on your leg and we’ve come here to this place called a hospital to make it better. Mummy and Daddy are here and we will look after you.’

It will of course depend on how old your baby is as to how much they actually understand. But even a small baby will hear something in the tone and sound of your voice that will reassure them in the same way as you might reassure them when they are ordinarily unwell or distressed. This will help them when they are in pain or have to have a procedure that may be frightening. Your presence and your voice will support them through this and if your words dry up because you are stressed of course there are people here to help you.

Why is this important?

You may have found that your baby’s behaviour has changed whilst in hospital. This is very understandable if they are feeling unwell or in pain.

Your baby’s behaviour may also be an expression of their worry that everything has changed even mummy and daddy and they cannot understand why. Repeatedly talking to your baby in a straight forward, truthful and simple way will help. You may find you need to reassure your baby much more than usual and perhaps in areas where before they seemed confident.

Your baby may be reluctant to leave your side or even seem to prefer one parent over another.

He or she may become irritable and nothing that you do is right for them. You may notice that your baby clings more or seems to go back to behaviours he or she used when he or she was younger. This is not unusual and it will pass as your baby begins to settle into the routine of hospital.

Common Questions:

What can I do?

Using your voice will help soothe your baby and it may also help to have a familiar or favourite toy or blanket. If at all possible try to follow something of the routine you had at home. It may be reassuring if you can offer familiar foods. These ordinary but well known things can help the baby feel safer in a world where so much has changed.

Will presents help?

It is helpful to have treats and presents, but it is important not to lose the firm and loving boundaries around behaviour that help babies and children feel safe.

Should I tell my baby we are going to hospital?

Yes if you are able it can help to prepare your baby for hospital stays or appointments.

Tell your baby two or three hours before you need to leave or the night before if you must leave the next morning. It will help if you use similar words and to reassure them that you will be with them.

Talking helps a baby manage hospital procedure better

Talking to your baby may help them deal better with the necessary medical procedures.

For example let them know a little in advance that they are going to radiotherapy. After a time this can become routine and then it will be less frightening.

If your baby is very absorbed in playing it can help to avoid upset if they are given advance notice that they will have to stop to go for treatment. Remind them that they can play again later.

Don't offer false reassurances or your baby will lose trust. Even if your baby is anxious about a procedure tell them before it happens. Don't be tempted to pretend something else is happening. Be honest and tell them what is going to happen and reassure them that you will be with them. This will help your baby manage better as he or she will know they can rely on you.

Straightforward, honest explanations will develop your baby's sense of safety.

Central lines and other procedures

It may make things easier if he or she understands why their central line or 'wiggly' as some little children call it (you may find your own name for it), must be accessed several times a day. Why the nurse comes in to check their temperature and so on.

You can talk about it whilst the nurse is there and this will reassure your baby and become a part of their new daily routine.

Even tiny babies like to be talked to

Even with a very small baby you may find that it helps you to talk to him or her, to explain why so much has changed. Your voice will soothe your baby and looking at him or her will help reassure him or her too. Helping your baby become more resilient will enable them to manage the evitable changes and challenges of cancer treatment. You may find that it helps you and your partner or those close to you when you talk to the baby. It may allow you to talk together too.

Summary

- **Talk with your baby**
- **Explain what is happening even to a very young baby**
- **Bring some familiar items from home**
- **Keep your boundaries it will help your baby feel safe**



We are here to help

We understand that you have to feel in the right place emotionally to be able to talk in an honest and open way. Stress has a way of drying up our capacity to think as well as talk. If this is the case there will be professionals in your hospital who can help.

Please do not hesitate to ask one of the specialists for extra support if you are struggling. All hospitals will have access to support for you. Some hospitals will have a team of psychotherapists and psychologists to support you, your baby and you family.

This leaflet was produced by the ACP (Association of Child Psychotherapists) and was written by Jane Elfer, a Child and Adolescent Psychotherapist with years of experience of working with children and their families who have terminal illnesses. Please contact the ACP if you want more information about child psychotherapists in your area or linked to your hospital.

For more general information about child psychotherapy and the ACP go to: <http://www.childpsychotherapy.org.uk>

Follow us on Twitter  ACPbulletin



The Association of Child Psychotherapists.

Suite 7, 19-23 Wedmore Street, London, N19 4RU
admin@childpsychotherapy.org.uk www.childpsychotherapy.org

Designed and printed by MPC Print Solutions
Tel: 020 8440 2340 Email: sales@mpcprintsolutions.com www.mpcprintsolutions.com

