

Care Planning in Advance

Throughout your child's care, you will have been developing plans for their care based on assessments made by the team caring for them. As your child's condition becomes more unstable or starts to deteriorate, the professionals may want to develop other plans to deal with that deterioration or instability. These plans are called by different names by different teams.

Anticipatory Care Planning

An Anticipatory Care Plan (ACP) sets out what actions should be taken when your child's condition becomes unstable or deteriorates or they develop potentially life-threatening complications of their illness. The actions should be discussed and agreed by you and your child (when appropriate). It is important that someone explains to you the choices you have in the care your child receives.

If your child is approaching the end of their life, this planning is particularly important and these plans are sometimes called Advance Care Plans or End of Life Plans. The purpose of these plans is to try to ensure that your child's care runs smoothly and in accordance with your wishes. This may, for example, ensure the care happens in a place that you choose or prevent inappropriate admissions to

hospitals. Planning ahead will mean that you don't have to think about so many practical things at the time of your child's death, when you will want to spend as much time as possible being with your child and when you are likely to feel exhausted and confused.

How will I cope?

It is natural to have lots of questions, concerns and fears about this stage of your child's care, and you will need lots of information about your child's condition and what to expect. You may wonder:

How will I tell my other children, family and friends?

How will we care for our very sick child?

What is going to happen?

What are the practical steps I need to take?

Don't be afraid to ask for help. Families have told us that forward planning for their child's end of life, although really difficult, can make them feel more in control of the situation and can give them more time to create positive memories during the last few days.

What will an ACP include?

The team caring for your child will be there to support you and will be able to answer the questions you have. Before you meet them you might want to think about what questions you want to ask. You might find it easier to write a list of all the things you are worried about or want to know.

Here are some of the questions you might want to discuss:

- What care is available and where can it be provided?
- Is it available 24hrs a day, 7 days a week?
- Who will be there out of ours to care for your child?
- What sort of steps do you want the team to take if your child needs resuscitating or if they suddenly deteriorate? Will it be possible to withdraw invasive treatments and equipment and allow a more natural death?
- Do you have any views on organ and tissue donation? Do you need more information about this? Even if your child has had a long-term illness, it is still possible to donate tissues such as heart valves and corneas.
- A plan for managing your child's symptoms should be in place, who will manage this?
- Who do you want to be there at the time of your child's death? Who will look after your other children? Who will call family and friends?
- Where do you want your child to be cared for, at the time of death, and after death? There are a number of choices you can make, including taking your child to a special suite at a children's hospice or taking them home.
- What kind of ceremony (ies) would you like? You may want to have a special naming ceremony, an informal celebration or a traditional funeral; you may want to plan more than one, or you may not wish to have any.
- Does your child wish to make a will? Your child may find it comforting to write a will, choosing to give their toys or possessions to specific friends or family members.

Think about who else you would like to be with you at the discussions. It's always best to have a friend or other family member with you.

Don't be afraid to ask for time to think about these important choices you are making, or to ask for more discussions with the staff involved in your child's care.

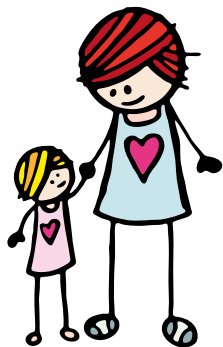
Keeping and reviewing the plan

Your care team should work together with you, your child and the rest of your family to develop a written end of life care plan. Make sure everyone working with your child has a copy of the plan, so they can act in accordance with your wishes. It is important the plan is reviewed regularly – you can change your mind at any point about any aspect of the plan.

Keep a list of useful contacts close by

It's good to keep a list of all the professionals involved in your child's care. Make sure you are given out-of-hours contact numbers so you have peace of mind day and night. If you are worried about anything and can't wait to see your child's specialist – talk to your GP. In a medical emergency call 999.





Together for Families Helpline
7am-Midnight, 7 days a week

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