



Why has my child been referred?

When considering Advance care planning we will provide you with a longer opportunity to meet and talk with your Consultant or a Consultant with an interest in life-limiting conditions and a Children's Palliative Care Specialist Nurse. It gives the chance to discuss possible treatments if your child's health deteriorates, offer practical advice and support, help with managing symptoms such as pain and help with coping with the emotional stress of caring for a child with a life-limiting condition.

Why has my child been referred for Paediatric Advance Care plan now?

Discussions about what might happen in the future are never easy, but difficult discussions are often easier when your child is relatively well. It can be very difficult to make decisions in an emergency.

What is a life-limiting condition?

A life-limiting condition is one which cannot be cured and from which the child or young person is likely or expected to die in childhood or young adulthood (before their 40th birthday).

Does this mean my child is dying?

No. Children with complex healthcare needs may be referred for consideration of an PAC-Plan at any point along their illness journey depending on their individual needs.

What is Paediatric Advance Care plan?

Sometimes families worry about what might happen if their child's health deteriorates suddenly or unexpectedly. Talking through what might happen can help reduce some of this concern and anxiety.

Such discussions will include considering the types of treatments that might be available, and the possible benefits and harms of particular treatments. We will consider whether for your child there are treatments that would be helpful and perhaps some treatments that would not be helpful. It is essential that these discussions are centred on your child, their needs and their quality of life – what your child's life is like for them.

The aim is that your child will always be treated with dignity and be as comfortable as possible. We will always aim to relieve distressing symptoms. We will aim to support you and help

you to provide as much of the medical care and treatment as you want.

Planning for an unexpected change in condition is difficult, but parents have found it can be easier to balance ideas, think clearly and discuss issues in advance. It can be very helpful to make some decisions beforehand so that if there is a sudden deterioration in your child's condition, treatments that you have already considered and discussed can be given.



How will the Paediatric Advance Care plan be made?

We will work together with you at your own pace to put together a plan for the emergency care of your child. You may also want to involve other key people (family, friends, religious leader or professionals such as a key worker, community children's nurse or Hospice representative) directly in the discussions.

You have been given this leaflet as you may wish to think about what is important for you and your family prior to your consultant's appointment/visit. You may wish to write and bring some notes or questions. It may be appropriate to involve your child in the discussions.

When you are happy with the PAC-Plan for your child, a copy will be given to you. With your permission, copies of the plan will then be given to professionals who help to care for your child.

If your child requires emergency care, the PAC-Plan will be available to guide treatment along the lines you have already discussed.

How will the Advance care plan be kept up to date?

As your child's health will change over time, the Plan will be reviewed regularly, every six months to a year to make sure it is kept up to date. Some treatments that are considered reasonable in the early stages of an illness, when the child is enjoying a good quality of life, may need to be reconsidered later. It may be that the burdens of such a treatment (such as the need to be in hospital, or how difficult a treatment is) may be less appropriate later in the illness.

What if I want the PAC-Plan to be reviewed or I want to come off the scheme?

You, or the professionals involved in your child's care, can ask for the PAC-Plan to be reviewed or for it to be removed at any time.

We would like your child and family to feel that they have had time to discuss all possibilities. You may need several meetings to talk about all the options. These decisions do not need to be made in a hurry. It is important to make an paediatric advance care plan for your child that you are happy and comfortable with. We hope that you will find the meetings and the opportunity to discuss the PAC-Plan for your child helpful.

If you decide to go ahead with the PAC-Plan, please let us know your experience for future children and families.

Please send your comments to:

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Paediatric Advance Care Plan (PAC-Plan) for Children & Young People

