How do I look after the ‘just in case’ medications?

These medicines will be in a locked box. Keep them in a safe place out of reach of children or vulnerable people.

The nurses will check these medications are in date every month. They will also check that the ‘just in case’ prescriptions are still appropriate for your child.

How often will the team see my child?

The amount of visits during the day depends on your child’s condition and the amount of support you feel you need to keep them at home. The team has to see your child at least once a week so they can make sure they are treating any changes to your child’s condition quickly and so they can provide detailed information to the nurses on the on call shift.

Will a palliative nurse always see my child out of hours?

Not necessarily. The Children’s Community Nursing Team support the Palliative Team to deliver the 24 hour on call. This is to make sure we can offer the on call 7 days a week. All nurses on call are given detailed information about your child and their condition so they know what your wishes are and how to manage any symptoms that arise.

Can the nurses speak to somebody that knows my child overnight?

The Palliative Team will discuss with you who is the Lead Consultant that knows your child the best. This Consultant will be informed that your child is going on the 24 hour on call rota and that the nursing team may need to talk to a doctor within the Consultant’s team overnight to get advice on managing your child’s symptoms.

We also have a Consultant in Paediatric Palliative Care that we will arrange for you to see once your child is on the 24 hour on call. This visit will be within the normal working hours of the service.

Will my GP be involved?

We will inform your child’s GP that you have access to the nurses 24 hours a day. The nursing team can visit your GP surgery to discuss our service with them or a member of the nursing team can come to your house when your GP visits.

Your GP may be asked to provide medications and prescriptions to treat your child at home. We will also ask them to visit you and your child every 2 weeks so they can support you and your child through their palliative care journey.
The team will discuss with you what symptoms your child may face as their condition changes. We need to plan to treat on a number of symptoms that may occur. Frequently we plan to treat symptoms that never occur, however we have to do this because it can be very difficult to get prescriptions or medications your child may need overnight. If we don’t plan ahead we may not be able to continue to treat your child at home.

The team will arrange for a number of ‘just in case’ medications and prescriptions to be brought to your home.

**What is the 24 hour on call for?**

The 24 hour on call is for families that have a child that is thought to be in the last days, weeks or months of life. The extended service makes sure you/your child receives face to face nursing/emotional support 24 hours a day.

Some children and young people are on our on call for a long time. They have several periods of being very unwell, and then improve, particularly if they have a metabolic or neurological condition.

The 24 hour on call service enables you/your child to stay in your place of choice. Through discussions with you, your family and the professionals that know your child, it is recognised that your child’s condition is getting worse and you/your child have told us you don’t want to keep going to hospital.

**What does this mean for you?**

This means that in addition to our telephone advice, given outside normal working hours, you can request a nurse visits overnight if they are unwell, or need nursing intervention that cannot wait ‘til the morning.

**How will the nurses treat my child?**

The aim of the 24 hour on call service is:

- To deliver a service that meets the needs of your family
- To manage symptoms quickly and effectively
- To provide care in your and your child’s or family’s place of choice
- To make sure you have the right support when you need it

**Why is my child on the 24 hour on call visiting service?**

The 24 hour on call visiting is for families that have a child that is thought to be in the last days, weeks or months of life.

The extended service makes sure you/your child receives face to face nursing/emotional support 24 hours a day.

Some children and young people are on our on call for a long time. They have several periods of being very unwell, and then improve, particularly if they have a metabolic or neurological condition.

**What is the 24 hour on call for?**

The 24 hour on call is for families that have a child that is thought to be in the last days, weeks or months of life. The extended service makes sure you/your child receives face to face nursing/emotional support 24 hours a day.

Some children and young people are on our on call for a long time. They have several periods of being very unwell, and then improve, particularly if they have a metabolic or neurological condition.

**Usually these medications will be to treat:**

- Pain
- Sickness/nausea
- Breathlessness
- Anxiety, restlessness
- Seizures