

# Royal Hospital for Children and Young People Outreach Service: Homecare package information

## Information for parents and carers

---

The Royal Hospital for Children and Young People (RHCYP) Outreach Team provides home nursing support for children and young people with exceptional health care needs in Edinburgh and the Lothians. The team provides support for children and young people who have been assessed as requiring continuing care to return and remain at home, and minimise the time they need to spend in hospital. Care packages are agreed by the Lothian Exceptional Needs Support Group (LENS Group) and are funded jointly by health, education and social work. The Outreach nurses and support workers work in the family home delivering the agreed and appropriate care.

The purpose of this pack is to:

1. Give you information on the agreed Care Package, the service you can expect, and the planning, communication and review processes
2. Establish a shared understanding of the needs of your child or young person and your family, and the operational requirements of the Outreach Team.

**Note:** Care Package refers to the support you receive from health, education, social work and others, to help you care for your child/young person at home, ensure they are included in family and community life and ensure access to education. This package may include respite care, which gives an additional positive experience for your child/young person while allowing you and your family a short break from the demands of care.

### The Outreach Service- overview

This document outlines the service that the Outreach team aims to provide and the support that staff need when working in your home. **Please take time to read the Pack and discuss it with the Outreach Charge Nurse or Team Leader.**

The Outreach Team is a service provided by NHS Lothian. We are a team of Healthcare Support Workers led by experienced nursing staff who help support families caring for a child/young person with exceptional health needs at home/school or nursery.

We will:

- Work in partnership with you and your child/young person, to provide a service that aims to meet your needs and is sensitive to your lifestyle
- Ensure good communication between your family and the care team
- Provide competent care, given by staff with the training and skills to meet your child/young person's changing needs
- Build a good working relationship based on respect, trust and confidentiality.

## **Our roles:**

<b>Outreach Charge Nurse</b>	<p>Manages the team and along with the Team Leaders. They will recruit and allocate staff, and ensure that all the care packages are delivered safely and effectively. They will manage unforeseen circumstances such as sickness, including adjusting rotas to best meet the needs of all children/young people and families with care packages.</p> <p>If needed, they will meet with you to discuss any issues or concerns.</p>
<b>Outreach Clinical Skills Facilitator</b>	<p>Will organise and facilitate learning and training for the staff in your child/young person's package of care. They will give you as much notice as possible of any changes in your team, or any difficulties in covering the planned hours.</p>
<b>Team Leader</b>	<p>Will work with you to plan care and monitor how well things are going. They will get to know you and your child/young person, help plan care, and alongside the Clinical Skills Facilitator, they will train and supervise staff.</p> <p>They will work with you to prepare or update the Care Plan for your child/young person and they will agree the Short Notice Action Plan with you, detailing actions to be taken in the event of staff sickness or absence. They will meet with you regularly to discuss progress and provide advice and support.</p> <p>Each child/young person is allocated a Team Leader who has experience in caring for children/young people with complex health needs. They will be based locally (e.g. in Calareidh or Sunndach).</p>
<b>Health Care Support Workers (HCSW)</b>	<p>Will be trained specifically to meet your child/young person's needs. Training is reviewed regularly as needs change and when new staff join the team.</p> <p>They will provide hands-on care as agreed in the child/young person's care plan to help you meet your child/young person's health needs and ensure social and emotional development. They will complete all relevant documentation and inform you and other team members of any concerns. They will check and clean equipment and help maintain a safe working environment.</p> <p>This team will change over time as staff leave or move to other packages.</p>
<b>Nursing students</b>	<p>The Outreach Service also occasionally includes students who work a placement with the service as part of their University education. The students are mentored by the Team Leaders and are supervised by staff within your package. We ask that you allow student nurses to work with your child/young person to gain valuable experience working with children/young people with exceptional health care needs. We will inform you, the school and or nursery in advance if student nurses will be working alongside staff in your package.</p>

In order to provide the best possible cover we need to have a reasonably large pool of staff trained to work with your child/young person. At times this may feel like there are a lot of staff in your home but we ask that you allow staff training in your home and the Team Leader or trainer to visit and assess staff. We will give you advance notice of any planned visits. These visits also give you an opportunity to discuss any care issues you may have. The lack of sufficient trained staff in your child/young person's package could result in unfilled shifts.

As a parent or carer you always have prime responsibility for the care and welfare of your child/young person. The Outreach Team are there to support you and not to take over control. In the coming weeks please help the team build a picture of your preferences and routines to help them get to know you and share your home. It can be difficult having staff working in your home so good communication is very important.

Some important issues are listed below:

- The Team Leader will agree simple **House Rules** with you, so that the HCSWs know your preferences.
- You are the expert in your child/young person's care. If the HCSWs have difficulties they will ask you for advice or support.
- We respect your need to rest. Over-night care will give both you and your child/young person time to sleep but, if the HCSWs are concerned, they will wake you to ask for advice or support.
- We will make every effort to ensure that the team provide care at the agreed times. On occasions we may need to offer you alternative trained staff to cover sickness, vacancies or unexpected demands. The Outreach Charge Nurse or Team Leaders will give you warning of any problems and the steps being taken to provide support. As a last resort, when it is impossible to cover a shift, a trained family member will need to care for your child/young person.
- Where an important decision has to be made, the person with parental responsibility must make it. Please consult with medical staff where necessary.

All care packages require another responsible adult to be in the home with the carer at all times in case of emergency or to help with moving and handling.

## **The care plan and changes to your child/young person's health**

The Team will help you perform routine and emergency care for your child/young person as described in their **Care Plan**. This outlines your child/young person's routines, communication needs, likes and dislikes and the care advised by the medical and therapy teams. Care is based on NHS Lothian Policies and Procedures, as used at the Royal Hospital for Children and Young People, Edinburgh.

Staff will only deliver the care documented in this care plan. The care plan will change, as your child/young person's needs change. Your **Team Leader** will be responsible for keeping it up to date. Please let them know if any adjustments are needed, particularly after a visit to hospital.

Please keep the care plan folder accessible so that staff can read and update the plan as necessary. Staff will make notes of the care they give on each shift to help ensure your child/young person's needs are assessed and met, and that any changes are communicated (these will either be written or recorded on NHS Lothian's digital patient information system-TRAK). Each package will be supplied with a laptop for this purpose. The records will be used when reviewing your child/young person's care package. Any review documentation will be shared with you before being presented to the LENS group by your Community Children's Nurse (CCN).

Staff will be alert to any change in your child/young person's health and will discuss concerns with you. Please seek urgent advice from other members of the care team or contact the emergency services if needed. If you are not available, or staff have serious concerns, they will seek advice from the Outreach Charge Nurse/Team Leader, Clinical Co-ordinator at the hospital, other members of your care team or the emergency services.

## Medical equipment

Please make sure that the medical equipment needed to care for or protect your child/young person is easy to access and that staff have the space and lighting to use it safely. All care equipment must be regularly serviced, and users must be trained to use it. The equipment provider (Health, Social Work or Education) should arrange this but let your CCN or relevant healthcare professional know if you have concerns.

## Important information about the Outreach Service

The team will work closely with you, to provide the care that your child/young person needs in a way as sympathetic to your lifestyle as possible. Your Team Leader will make regular contact with you. Please contact them if you have concerns.

- **Privacy:** The HCSWs will only go into the parts of your home that they have permission to use. Please feel free to ask a carer to leave the room should you wish to be alone with your child/young person or other family members. We appreciate that all families need private space.
- **Confidentiality:** The HCSWs will respect your right to confidentiality. You will only be asked for information that is needed to plan and deliver care. The Team Leader will agree any information to be shared with the team and add this to the care plan. We also need to respect the confidentiality of other patients and families, and the staff themselves. Please do not ask HCSWs to discuss personal or private information or to give you personal contact details for themselves or other families.
- **Your concerns:** Issues or concerns can always be discussed in confidence with the Outreach Charge Nurse or Team Leader who will try to resolve any difficulties as quickly as possible.
- **Child Protection:** All staff in NHS Lothian are committed to ensuring the welfare of children and have a duty to act upon concerns about any child/young person's welfare, safety and protection. In such circumstances they are obliged to share their concerns with their manager or a designated professional.
- **Professionalism:** Our HCSWs need to maintain a professional working relationship with you and your family. HCSWs are not permitted to attend your family events unless they are accompanying your child/young person as part of their normal duties.
- **Respect and courtesy:** We expect staff to act in a professional manner at all times, to respect you and everyone in your household, your home, possessions, and your domestic routines. Please contact the Charge Nurse or Team Leaders if you have concerns with staff language or behaviour. Likewise we ask that you treat our staff with respect. NHS Lothian does not tolerate the use of inappropriate language, tone or behaviour towards staff and this may result in the removal of the service.

Team Leaders will prepare a staffing rota and you will receive notice of the staff working with your child/young person on Friday for the following week.

- **Requests and cancellations:** Outreach staff receive their rota 4-6 weeks in advance, this means that any requests to change shift times can only be accommodated if staff are agreeable. Please contact the Outreach Office as early as possible if you wish to change or cancel shifts. Please do not approach staff directly to request a change in their shifts. The HCSWs are contracted to work set hours so it is not possible to 'save' or 'bank' unused hours for a later date.

The hours of your child/young person's package of care has been risk assessed as necessary to support your child/young person at home so any cancellation of shifts will be reviewed by the wider team.

Any alterations to the hours (i.e. increasing or decreasing those hours) should be discussed with your child or young person's Community Children's Nurse in the first instance.

- **Emergency support:** There may be times when events mean you need extra help urgently. Team Leaders and the Outreach Charge Nurse will be able to advise you on the support available from the Outreach Service- but the request for extra support should be made through your child or young person's Community Children's Nurse in the first instance.
- **Staff availability:** We will agree a **Short Notice Absence Plan** with you; so that you know the steps we will take if there is a staff shortage. **This plan will be discussed and agreed with you.** At times, sickness or other problems may mean that staff from your team cannot cover all shifts. The Outreach Office will contact you at the earliest opportunity to discuss the alternatives. As a last resort, if no other arrangement can be made, you may need to cover short-term sickness yourself.
- **Staff sickness while on duty:** Please inform the Outreach Office or RHCYP Clinical Coordinator (out of hours) if a member of staff fails to arrive or is taken ill and is unable to continue to work. If they become unwell during a shift you will need to take care of your child/young person to allow them to leave.
- **Family holidays:** We will provide support in your main home, school or other agreed place and we may be able to provide support elsewhere (i.e. for a holiday in the UK or abroad) but we cannot guarantee this. Please discuss your needs with your Team Leader at least 2 months in advance of any planned holiday (refer to guidance notes for parents).
- **Unplanned admission to hospital:** There may be times when your child/young person needs to attend Accident and Emergency (A&E). The HCSW will inform the Outreach Office and accompany you and your child/young person to A&E if needed. Outreach responsibility ends if your child/young person is admitted to hospital. It may be possible for Outreach staff to remain in hospital with your child/young person if required by the hospital. The Outreach Charge Nurse will discuss this and negotiate with the Ward Charge Nurse/Clinical Coordinator. Hospital staff always have the primary responsibility for your child/young person's care whilst they are in hospital.
- **Planned admissions to hospital:** Outreach staff will not routinely work with your child/young person during a planned hospital admission. On occasion the hospital may request assistance with staffing from the Outreach team. The Charge Nurse or the Team Leaders will discuss this with the Hospital Co-ordinator.

A Team Leader will agree day-to-day working arrangements with you, and share this information with the team. Any request to alter the package of care (e.g. increase or decrease hours) should be made to your child's community nurse. When staff are working in your home please ensure a safe working environment by providing adequate seating, lighting and heating in the rooms where care is given. Staff will also need access to hand washing facilities and a lockable toilet. They will bring their own food and drink but use of your kitchen would be much appreciated.

- **Breaks:** Staff need to take a minimum of 20 minutes break after 6 hours of work. Please relieve them to allow this in the daytime. At night, staff will arrange their work to take a break within listening distance of the child/young person.
- **Dress code:** Outreach staff wear a uniform while on duty. Staff must wear appropriate footwear in order to carry out their normal duties- if you do not want staff to wear their outdoor footwear in your home in please contact a Team Leader who will arrange with staff to bring clean footwear or overshoes to wear whilst on duty in your home.
- **Non-nursing duties:** Please do not ask members of the nursing team to undertake any tasks that are not related to your child/young person's health needs, for example:
  - Domestic tasks such as: cleaning, ironing, cooking and washing clothes
  - Care or babysitting for any other child/young person in your house
  - Transport of a child/young person or any family member in their own car. Staff can perform escort duties in your family car if agreed as part of the Care Plan.

We expect staff to ensure the room and equipment are left in a clean and tidy state, ready for you or another member of staff to take over. Bins should be emptied, dirty laundry placed in your washing basket and any used crockery cleaned, dried and put away. Please tell the Team Leader if you have any problems with this.

- **Health and safety:** Please be alert to any home hazards such as tripping or slipping risks, unsafe flexes, appliances, or overloaded electrical sockets. We require that you have a functioning smoke alarm. The Lothian Fire Service will provide alarms, do a free home safety check and help you devise a simple fire evacuation plan.

To help ensure everyone's safety, staff must report any hazards or incidents arising at work. They will take immediate action to make the situation safe and report their concerns to you. Verbal and written reports will be made and followed up by the Charge Nurse/Team Leaders. Each year we will review the health and safety risk assessment for your care package.

## What are the responsibilities of the RHCYP Outreach Team?

An identified team will endeavour to provide support (subject to point 4. below), at the agreed times and places. We cannot guarantee support in other locations, especially if outside Lothian.

1. We will work with you to develop a Care Plan that describes your child/young person's needs. The Care Plan and staff training will be updated as these needs change.
2. We will ensure that staff have the skills to deliver the care necessary for your child/young person's health and development.
3. We will give you as much notice as possible of the staff allocated to each shift.
4. In the event of staff sickness, vacancies or unexpected demands, the Outreach Charge Nurse or Team Leader will inform you of the steps they are taking to provide support. Every effort will be made to find alternative trained HCSWs but, as a last resort, if it proves impossible to cover a shift, you or a trained adult will need to care for your child/young person.

5. The HCSWs will be alert to changes in your child/young person's health and will discuss these with you. If, in the view of staff, your child/young person's health suddenly gets worse, you should contact the emergency services.
6. Our staff will respect your right to confidentiality and privacy. You will only be asked for information that is essential for the delivery of the service, and staff will only go into parts of your home where they have permission to be. HCSWs will respect you and everyone in your household, your home, possessions, and your domestic routines.
7. The Outreach Charge Nurse and Team Leaders will monitor all aspects of the service and maintain regular contact with you, through home visits and by telephone or email.

## **What are your responsibilities in sharing care with the Outreach Team?**

- As parents or carers you always have prime responsibility for the care and welfare of your child/young person. The Outreach staff are employed to support you and not to take control. Where an important decision has to be made the person with parental responsibility must make it.
- Help the team build a picture of your family's needs and preferences so that they can provide the care you need in the way best suited to your child/young person and your lifestyle.
- Please provide advice or support to staff if they encounter difficulties.
- Ensure access to care equipment and the space and lighting to use it safely. All care equipment needs to be routinely serviced. Your Community Children's Nurse will help ensure this.
- Be safety aware and alert staff to any hazards in your home or the immediate area. Our team will make a risk assessment and give safety advice.
- Please provide appropriate seating, lighting and heating in the rooms where staff will work, allow meal breaks and ensure access to the kitchen and a lockable toilet.
- Do not ask members of the team to undertake any tasks that are not related to your child/young person's health needs, such as domestic duties or the supervision of other children/young people.
- Please treat our staff with respect. Do not ask them to discuss other families or members of staff, or to give you personal contact details.
- Please try to give as much notice as possible of changes in your usual shift pattern. Unfortunately, it is not possible to save or "bank" unused hours for use at a later date or change shift times at short notice.

## **Your concerns**

The aim of this Information Pack is to help us work together to care for your child/young person. Please let us know if you are unhappy with any part of the package so that issues can be resolved as quickly as possible. Concerns can be discussed in confidence with the Team Leaders or the Outreach Charge Nurse.

If you are unable to talk to the staff involved in your child/young person's care you can ask to speak to the Community Clinical Nurse Manager (RHCYP 0131 312 0737) during working hours.

If it is out with normal working hours and you feel your concerns need to be dealt with immediately, then please contact the hospital Clinical Co-ordinator (RHCYP 0131 536 0000).

More information can be found in the leaflet *Making a complaint about the NHS*, available wherever you receive NHS care or on the Health Rights website:

<https://www.nhsllothian.scot/YourRights/ComplimentsConcernsComplaints/>

Or by contacting:

The NHS Lothian Patient Experience Team  
Waverley Gate  
2 – 4 Waterloo Place  
Edinburgh  
EH1 3EG

Telephone: 0131 536 3370,

Email: [feedback@nhsllothian.scot.nhs.uk](mailto:feedback@nhsllothian.scot.nhs.uk)

## Our concerns

If we have concerns about delivering care in your home or elsewhere, or about the safety of staff, the Team Leaders or the Charge Nurse will arrange a meeting with you to resolve the issues as quickly as possible. If a solution cannot be found the Charge Nurse will inform their manager and arrange a meeting with you and the staff who organise and provide your care package. This meeting will consider ways to resolve the difficulties. If necessary, senior managers and doctors may be asked for advice.

Care at home is provided as a benefit for your child/young person. If we have serious concerns regarding the health or safety of your child/young person or our staff we may need to discuss alternative ways of meeting your child/young person's needs. This may include alteration or withdrawal of the homecare package. In the event of a serious threat to staff health and safety, NHS Lothian may need to withdraw the homecare service at short notice.

## Contact details

### Outreach Office

Calareidh  
35 Bingham Drive  
Edinburgh  
EH15 3LA

**Opening hours:** 7am to 5pm Monday – Friday  
8am to 11.30am on weekends and Public Holidays

For urgent care package advice at other times, contact the RHCYP on **0131 536 0000** and ask the switchboard to bleep the duty Clinical Coordinator.

The Outreach Team can be contacted on the Outreach mobile number: **07903 969 695**

Your Team Leader will give you their mobile number when they have been allocated to your child/young person.

For urgent health problems follow the advice in your child/young person's Personal Care Plan, contact your GP, NHS 24, Hospital or emergency ambulance as appropriate.