

Suction: The Diana Service has suction machines available for end of life care, which can be taken to the family and instruction provided on how to use it.

Medication: Medication may be useful to keep children comfortable. The hospital pharmacist can advise on medication for the child at home. If medication needs to be administered by the Diana Service, a drug chart will be needed. The Diana Service will ask for anticipatory medication to be written up with two step up doses. Medication is prescribed following guidance from the Association for Paediatric Palliative Care: Medicine Master Formulary 2015 (3rd Edition) which is available on line following the link below.

<http://www.appm.org.uk/10.html>

It is often difficult for the child's Lead Consultant to be available to write up medication as symptoms change therefore we ask if they can consider contacting Rainbow's Hospice Medical Team, who have the expertise in Symptoms control, to give authority for them to support the families GP in prescribing medication. Rainbows can be contacted on 01509638000.

Feeding: As a child deteriorates their ability to tolerate feeds will reduce. Whilst it is important to ensure the child's comfort there is also a need to have a plan for reducing their feeds as their symptoms dictate.

Planning for Deterioration: Having a plan of what to do when a child deteriorates before discharge saves time. For example, what to do if the child is not tolerating feeds or step up plans for medication.

5. Information

The Diana Service has information of what to do when a child dies at home. The team is experienced in going through this with the family or the family may wish to work through it themselves. It is imperative that the information is available to the family once the child is at home.

For general enquiries please contact us by:

- ✉ **Writing:** Diana Children's Community Service, Bridge Park Plaza, Bridge Park Road, Thurmaston, Leicester, LE4 8PQ
- ☎ **Telephone:** 0116 295 5080
- 📠 **Fax:** 0116 295 5081
- @ **Email:** feedback@leicspart.nhs.uk
- 💻 **Website:** www.dianaserviceleicester.nhs.uk

East Midlands Ambulance service

To obtain a blank PRP contact EMAS or call Diana Service.

The Diana service have details of how to distribute once completed.

www.emas.nhs.uk/contact/care-decisions

Tel: 0115 919 3483

Fax: 0115 919 3473

Airliquide

To order Oxygen for Home Delivery (within 4 hours for emergency orders).

Please call for support:
0808 2022099

You will be asked to complete a HOOF form. Please Fax form through to Airliquide and send a copy home with the family.

Home Oxygen Order Form available from:

www.airliquidehomehealth.co.uk/portal

In the event the child dies prior to being discharged please call the Child Death Review Manager on 0116 295 8724.

Acknowledgments

This booklet was compiled by: Julie Potts Community Children's Nurse on behalf of the Diana Service.

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Sending a Child Home to Die



Information for Hospital staff

Telling someone there is no more treatment for their child and that they are going to die is the worst news a parent will hear.

Parents will be traumatised by the news and may request that there is no further involvement from health professionals. Many may just want to get their child home to die as soon as possible. It is imperative that they are given an informed choice of the care, treatment and support available.

What can the Diana Service offer?

1. Emotional Support

Families may feel they will manage and just want to get home, but once home they may feel daunted and ill-equipped to deal with the situation. Staff from the Diana Service will be able to emotionally support the family, as they have had experience of dealing with other families in similar situations and will be aware of what support they need at home.

2. Physical/Practical Support

Families may feel they initially do not need any practical support at home. This can all change if the child's condition deteriorates over a longer period than expected. Children are uniquely individual and often don't die when predicted. The Diana Service can continually assess the family's needs and can implement support where appropriate e.g. respite, play/diversion, equipment needs, emotional support and psycho-social support for the child and the family.

The Diana Service can offer 24 hour on-call for the family at the end of life phase. (Guidelines available from the Diana Team on request).

3. Symptom Control

Telling the family there is no treatment for their child may be misunderstood. There may no longer be any active treatment to prevent the child from dying, however, there will be treatment available to manage symptoms to ensure they are comfortable during the end of life phase of their illness.

We understand that when the family hear the devastating news that their child is dying, they often want to get home as soon as possible but it is

important that they are aware of how their child's condition may deteriorate and how their symptoms can be managed effectively with the Diana team's support.

It would be beneficial for the family to be informed of the role of the Diana Service when the end of life news is broken to them. The Diana Service will work with the hospital team to facilitate the transition to home and ensure all equipment and medication is in place. This can often be achieved within a few hours, however, making more time available ensures a safer transition from hospital to home.

4. Information

The Diana Service aims to empower families to care for their child in their own way, by giving them an informed choice of the care, treatment and support available.

We are experienced in caring for dying children at home. We can go through what potentially can happen before and after death, as and when the family feel they need the information. Within the service we have a team who will focus on the emotional support of the parents and the siblings if needed, to provide pre and post bereavement support.

The Diana Service can activate a 24 hour on-call service for the family during the end of life phase of their child's illness, which includes planned home visits, visits when symptoms change and telephone support.

The Diana Service can provide information on the practicalities which need to take place before and after death to enable a child to remain at home. This can prevent chaos and unnecessary distress to the child and family.

Ensuring a Smooth Transition From Hospital to Home

1. Diana Service

Informing the Diana Service as soon as possible, preferably during the decision making process, prevents delays in getting the child home.

Please ask the family for the Diana Service to have permission to share information with Rainbow's Hospice. The two services work closely together to

ensure the family have all available care options and support available to them.

The Diana Service needs 48 hours notice to set up the 24 hour on-call service, however, we are aware that sometimes there is no time to delay in getting the child home. Informing the team as soon as possible will ensure the team can guide the hospital through the appropriate procedures and implement support as quickly as possible.

Informing the Diana Service before midday (weekdays) can quicken this process, as palliative care is seen as a priority.

2. General Practitioner

The GP must be informed and asked to visit the family as soon as the child is at home (preferably within the first hour). It is a legal requirement that the doctor who signs the death certificate has seen the child within the last 14 days to prevent it being treated as a 'Sudden Death'. If treated as a sudden death, the police, ambulance service and coroner will need to be involved and this may cause unnecessary distress for the family.

3. Ambulance Service

Personal Resuscitation/Emergency Plans should be completed and a copy kept with the child at all times. Please follow the information within the plan of how to distribute. You can also call the Diana Service for advice. This will give information to the Ambulance Team in case the family panic or are unable to manage their child's care on their own. Contact details are on the back of this leaflet.

Parents may say they will not call for an Ambulance, however, in a distressed state they may panic. Without this information, the Ambulance team will be legally required to resuscitate, treat and take the child to hospital.

4. Symptom Control

Oxygen: Most children will benefit from therapeutic oxygen at home if they are struggling to breathe. It may not improve their condition but it will help to keep them comfortable and give families a sense that they are helping their child. Oxygen can be delivered within 4 hours in an emergency.