

## After Your Child has Died.



# Useful Contact numbers involved in your child's care

## First Contact (if the Diana Service are on call for your child):

Times available:

## Diana Service

Times available:

If On-Call activated

On-Call not currently activated

## General Practitioner (Family Doctor)

## Ward

Times available: 24 Hours a day 7 days a week

## Other Useful Contacts:

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## Introduction

This booklet aims to provide useful information and advice to assist you during the early days of your bereavement. Please do not hesitate to ask if you are not clear about anything. We would be pleased to help.

This information has been supplied by The Diana Service as part of the Families, Young People and Children's Service as part of Leicestershire Partnership Trust, from a number of resources within Leicester, Leicestershire and Rutland. The information was compiled by Nurses who have first-hand experience of supporting families during this difficult time. It is information that has been fed back to us, which other families have needed in the early stages following their child's death at home (or in the community).

If you would prefer to go through this information with a member of the Diana Team, do not hesitate to ask. Any suggestions or comments you have regarding this booklet would be gratefully accepted.

The Diana Service seeks to meet the needs of all members of our community. If you have any special religious, cultural or other needs, please tell us.

## Practical Necessities: What to do first

Following the death of your child, there are certain things which need to be done. It is important to feel that you have a choice in what happens next. You may want to be by yourselves as a family, call upon friends and family or call professionals to offer support. This information should help to advise you of what you need to do.

## Who to Call?

### Diana Nurses or General Practitioner (GP)

When your child dies, following planned terminal care at home, there should be no need for the GP (General Practitioner or family Doctor) to be contacted immediately. You may wish to have some time together as a family first.

If you have been receiving the 'On-call service' from the Diana Team, you can ring the 'First Contact' to ask the nurses to come to your house.

Two nurses who are on-call will come together. It may be the case that the nurse's on-call do not live in close proximity of your address. Please be reassured that they will get to you as soon as they possibly can.

When the nurses arrive, they will do as much or as little as you want them to. This may include contacting your child's GP and your chosen Funeral Directors. (See 'How to Contact the Diana Nurses On-Call' on page 18).

**If the on-call service is not activated, you can call your usual ward for advice or ring the Diana Service. (See 'Contact Information' for times Diana Service available).**

### First contact

Name: .....

Tel: .....  
 .....

### Funeral Director

You will need to contact a Funeral Director. You can ask the Diana Team to help you with this. You don't have to wait until the Death Certificate is issued before doing this. Funeral Directors are usually very sensitive to your needs and will guide you with what needs to be done. It is important to check that you will be able to obtain the Medical Certificate detailing the cause of death from your GP before setting a firm date for the funeral. This is because it is sometimes necessary for the Coroner to be involved.

### Ambulance Service

The Ambulance Service has a legal obligation to treat your child if they are called to your home, unless you have a resuscitation plan that states otherwise.

However, when you are sent home for end of life care your Doctor will have discussed about resuscitation when your child dies at home. There is a form which will be completed with your input to inform them about your child. You will have a copy of the Personal Resuscitation Plan to keep with you in case you need emergency support.

The Ambulance Crew will then be able to support you without needing to actively resuscitate your child.

The Ambulance Crew will not take your child away from your home if you have a resuscitation plan in place however, they will take your child to the Leicester Royal Infirmary if that is your wish.

# Organ Donation

If you would like to donate your child's organs, please contact your GP or any Health Professional involved in your child's care. They will need to contact the **NHS Blood and Transplant National Referral Centre** to discuss whether your child's tissues could be used. As your child has died at home there is a limitation to which organs can be used. There are two which can be used within the first 24 hours following your child's death. These are as follows:

Corneas (Children over 3 years) and Heart Valves (Heart Valves cannot be used from children who had Cancer).

Both Tissues make life changing differences to people who receive them. Corneal transplant patients are often registered blind and once the transplant has been completed their sight is usually restored. Heart valves are often used on tiny babies with heart defects.

## **What happens if you decide to go ahead with donating?**

- 1.** The NHS Blood and Transplant National Referral Centre will take details from your GP or another Health Professional involved in your child's care.
- 2.** If the donation is possible you will be asked to give verbal consent over the telephone to the NHS Blood and Transplant National Referral Centre. Your message will be recorded.
- 3.** Arrangements will be made with you for your child to go to a suitable place for the tissues to be retrieved. This would be a hospital mortuary, Funeral Directors or similar setting. Your child could then return home if this is your wish.

**NHS Blood and Transplant National Referral Centre: 0800 432 0559**

They will be happy to give further information if you are considering Tissue Donation.

You may wish to keep your child at home after they have died. After the GP has visited, the Diana Nurses can assist you to wash and dress your child unless this is something you would like to do together as a family. Your child may have tubes such as Nasogastric, Catheters and Port-a-Cath Needles etc which can be removed at this point; however there are certain lines which may need to be kept in place (i.e. Central Lines).

You may want to keep your child at home for a short period of time or until the funeral. The Diana Nurses and Funeral Directors can give you support and advice about how to keep your child at home in the most appropriate environment.

There are a few things, which need to be considered when keeping your child at home. Your child's body will begin to deteriorate; therefore the length of time at home needs to be discussed with the professional involved. However it is ultimately your decision.

The best environment is for the room to be small with Air-conditioning units to ensure the room is kept very cool. The Diana Nurses can help with arranging for such units to be delivered to your home (turning off radiators).

If you want to keep your child at home for more than a couple of days the Funeral Directors will need to assess if your child's body needs embalming. (See Glossary of Terms) If your child is being cremated the cremation forms will need to be completed before embalming can take place.

Embalming usually takes a few hours. The Funeral Directors will come to collect your child from home and return them following the procedure. The Funeral Directors are very caring and will take your needs into consideration.

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## Alternatives to home

### **Rainbows Hospice**

Located in Loughborough, the hospice rooms have been designed specifically to enable your child to stay until the funeral. Your child does not need to have attended Rainbows in the past. If the room is available they often have a room for the family to stay at the hospice. Speak to the Diana Team about this option. You can view the room before making your decision.

### **Funeral Directors**

Your Funeral Directors will give you information about their own facilities regarding where your child can stay until the funeral. Please speak to them.



## Certifying the Death

Once you have contacted your GP (General Practitioner /Family Doctor) he/she will certify the death. The GP issuing the Death Certificate must have seen your child within the previous fourteen days to be able to sign the certificate. In exceptional circumstances, a problem may arise as to who can sign the Death Certificate. The Diana service and Funeral Directors will support you with this if the problem arises. Extra forms are needed if you chose to have your child cremated (see section on Cremation).

## Choosing a Funeral Director

The choice of Funeral Directors is important, as you should feel comfortable with them. You may already know which Funeral Director you will choose but, if you are unsure you can find contact numbers in your local telephone directories. You could ask family and friends as they may have recommendations or could investigate for you. They are often glad of something useful to be doing for you.

The Diana Service can offer support with selecting a Funeral Director although is unable to make any recommendations. If you have any difficulties the National Association of Funeral Directors will be able to advise you. Their Code of Practice is approved by the Office of Fair-trading. (See 'Useful Contacts' in this booklet for contact details).

You can ask any Funeral Director for an estimate of cost in advance of making any commitment to using their service. It is reasonable to ask for

at least two firms to quote a cost for you to compare, as charges can vary considerably.

Some funeral directors offer 'free' services for children's funerals; however there may be some costs if you have special requirements.

If you are struggling to meet the costs, the Funeral Directors can usually arrange payment by instalments. If you receive certain benefits or Tax Credits (Income Support, Council Tax Benefit or Disable Persons Benefit) you can apply for funeral payment from the Social Fund. The form SF200 can be obtained from the Funeral Directors.

**Other grants may be available. Speak to the Diana team who can look into this for you.**



## Once you have obtained the Medical Certificate (stating the cause of death), the death must be registered.

The Death must be registered at the local office of Registration of Births, Marriages and Deaths in the district where the death occurred. This needs to be done as soon as possible and usually within five days of the death (unless the Registrar agrees to a request to extend the period).

If the death has been referred to the Coroner, the procedure is slightly different and you will be advised accordingly.

Appointments last approximately 30 minutes. Anyone can register the death of the child as long as they hold all the appropriate documentation (Birth Certificate, Death certificate and personal identification). However, it is recommended that a person with parental responsibility is present.

Although it is usual for a parent to register a child's death, it is sometimes possible for a relative or friend to act on your behalf after discussion with the Registrar.

Which register office you attend depends on where your child dies.

If you are unsure, please ring the Leicester office, whose staff will be happy to advise you.

### If your child dies within Leicester City

#### Leicester Register Office

Town Hall  
Bowling Green Street Entrance  
Leicester

Monday - Friday **8:00am - 6:00pm**

Tel: **0116 454 1074**

### If your child dies within Leicestershire and Rutland

#### The Register Office

County Hall, Leicester Road  
Glenfield, Leicester  
LE3 8RN

Monday - Friday **8:45am - 16:15pm**

Tel: **0116 305 6509**

(They will advise you of an office local to you)

## What should you take to the Register Office?

- The Medical Certificate of the Cause of Death.
- Your child's Medical Card if possible.
- Any forms given to you if the death has been referred to the Coroner.
- Your child's birth Certificate.
- Approximately £10:00 for copies of the death certificate if required, which you will need for any private claims, insurance policies or other financial matters; normally two copies would be sufficient.

## What the Registrar will give you

1. A certificate for burial or cremation. This is what you need to give the funeral director before the final arrangements can be made. An additional certificate is needed if you are planning to have your child cremated. The funeral director will arrange to get this from the doctor.
2. Form BD8 (revised) - Notification of the Registry of Death. You would need this form if applying to the DSS for a funeral grant (see under Cost).

The registration and issue of these two forms is free. A certified copy of the death certificate is also available for a small charge. This is essential if arranging a funeral abroad or if your child had any savings accounts.

(If the Coroner has been involved you will have been given an order for Burial or a Certificate for Cremation.) The Funeral Director will need whichever form you are given so that the funeral can be held.

## Financial Assistance

If you receive certain Social Security Benefits (for example, Income Support, Housing Benefit and others) you can apply to the Social Fund for help to pay for the costs of the funeral.

You will need to complete an Application Form SF200. This is available from your Social Services Office, Post Office, most funeral directors or the hospital. There is a leaflet included with the form, which explains how to complete it and where to send it. You must include a written quotation, provided by your funeral director, with your application.

## Coroner

There are four main reasons why a case is referred to the Coroner:

1. A death has been sudden and unexpected.
2. A person has been ill but the doctor confirming the death is not certain why it happened at that particular time.
3. A death has been caused by a result of an accident or unusual circumstances.
4. Your child has not been seen by a GP/ Doctor within 14 days of Death.

The Coroner will look at the case and decide what happens next. They may order a post-mortem examination to determine the exact cause of death. If the Coroner is involved, a certificate to register the cause of death will be issued by the Coroners office.

The staff at the Coroner's Office are very helpful and will answer any questions you may have.

**You will only need to contact the Coroner's Office if you are asked to do so. (See useful Contacts).**

## Cremation

No-one can be cremated until the cause of death is definitely known. There are certain forms that need to be completed. Your General Practitioner needs to complete these.

1. The General Practitioner who has signed the Death Certificate needs to complete Part A of the Cremation Certificate.
2. Another Doctor needs to complete Part B. (The second Doctor cannot be from the same GP practice for legal reasons). Your General Practitioner should arrange this.

If there are any problems speak to one of the Diana Team or your Funeral Director who can organise for the appropriate forms to be completed.

Ashes can be scattered in a garden of remembrance or in a favourite place, although you may require permission from the landlord or person responsible for the land before doing this. They can be buried in a churchyard or cemetery, or they can be kept. Your funeral director will organise this for you. Arrangements may be made for erecting a plaque but there could be a charge.

## Burial

The Church of England has set fees for burials of which your funeral director can advise you. The cost will normally be higher for burial of someone who lives outside the parish.

Many churchyards are no longer open for burial because there is no space left in the grounds.

If a space has been paid for in the cemetery, there will be a deed of grant. Most non-denominational cemeteries are owned by either local authorities or private companies, so fees may vary.

## Burial abroad

If you want your child to be buried outside of England or Wales, the funeral director will be able to help you arrange this. Scotland, Northern Ireland, the Channel Islands and the Isle of Man are counted as 'abroad'. When you register your child's death, you will need to buy at least two of the certified copies of the death certificate (some consulates and embassies require more). You give these to the funeral director who will obtain an 'Out of England Certificate'.

## People to Inform

The Diana Service will be happy to help you contact people involved in your child's care, or you may choose to do this yourself as a family.

- Diana Service - who will inform all of the Diana Service members involved in your child's care. They will also inform The Child Death Review Team who legally need to be informed of all children who die between 0-18 years of age. The Child Death review Team will also inform Children's Services who will ensure all local health related appointments are cancelled.
- Any Hospitals out of Leicester that your child was attending.
- Local Social Services if you receive their services.
- Your Family Doctor/General Practitioner.
- Local company who supply medical equipment if you have any of their equipment, which needs collecting.
- Local Social Security Office to cancel allowances, benefits etc. You will get a special form from the Registrars Office to do this. (DLA stops immediately, Carers Allowance carries on for 8 weeks following Death).
- Oxygen Suppliers if applicable.
- Your child and siblings schools/Colleges.
- Enteral Feeding team if applicable.
- Passport Office, Libraries/clubs your child may attend.
- Wheelchair/Buggy Services.

### Removal of Equipment from your Home

The Diana Nurses will be happy to arrange for the removal of equipment by contacting the appropriate companies if you would like them to do so.

The Diana Team members can take any equipment which belongs to the Diana Service.

The Diana Team will advise you on how to safely dispose of any unused supplies and medication.

Controlled drugs need to be returned to your local pharmacy by a member of your family.

### Your Feelings

The death of a child is one of the worst things that could ever happen to anyone and no one can tell you exactly how you will feel. There is no normal or right way to be and most people experience a whole range of different emotions. Feelings may include disbelief, numbness, anger, sadness, guilt, emptiness and sometimes a sense of relief. These may all be so mixed up that you wonder if you will cope.

Although you may expect your partner (and/or family and friends) to pull together during these times, it is common for everyone to grieve in different ways and at different rates, and may find it hard to help each other. Support is available. The Diana Service will be able to offer support and will be able to refer you to organisations that have experience in dealing with the loss of a child.

### Children's Feelings

We are often afraid to talk to children for fear of upsetting them, but this leaves them alone with their fears and fantasies, which can be worse than reality. Children are often very sensitive, and will be aware of your sadness, even if you try to avoid expressing your grief in front of them. It may help to show your feelings and grieve together. It is important to be as honest as you can with children and include them as much as possible. Many children want the opportunity to be involved and to be part of funeral arrangements. They may want to assist in the order of service or write their thoughts down about their sibling, write poems, or pick favourite songs, which could be included. Children often enjoy putting together memory boxes to remind them of their sibling.

Many families wonder about explaining what happens at a funeral to siblings or other children who may attend. The Child Death Helpline Department can discuss this with you.

**There are various agencies that are able to support you and your children. Speak to the Diana team who will give advice. See also 'Advice and Support' for useful contacts.**

## BLISS

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**Support for parents of babies in Special or Intensive Care Units and for bereaved parents.**

68 South Lambeth Road, London, SW8 1RL

Helpline: **0500 618 140**

Website: **[www.bliss.org.uk](http://www.bliss.org.uk)**

## Compassionate Friends

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**For parents who have had a child of any age die; local self help groups offer mutual support. Helpful literature available.**

53 North Street, Bristol, BS3 1EN

Tel: **0845 123 2304**

Website: **[www.tcf.org.uk](http://www.tcf.org.uk)**

## Childhood Bereavement Network

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**Is a National Multi-professional federation of organisations and individuals working with bereaved children and young people.**

8 Wakeley Street, London, EC1V 7QE

Tel: **0207 843 6309**

Website:

**[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)**

## Child Death Helpline

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**Telephone helpline for anyone affected by the death of a child.**

York House, 37 Queens Square  
London, WC1N 3BH

Helpline Freephone: **0800 282 986**

Website: **[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)**

## Citizens Advice Bureau, Loughborough

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**Offers free impartial, confidential advice and help, including access to money and legal advice.**

John Store House, Wards End, Loughborough.  
(They will be able to inform you of their local office otherwise refer to your local telephone directory).

Tel: **0844 417 1025** from landlines  
**0300 330 1025** from mobiles

## Childline

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**Helpline for children and young people up to the age of 18 in danger, distress or with any other problems.**

Freefone: **0800 11 11**

## Coroner's Office

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The Town Hall, Town Hall Square,  
Leicester, LE1 9GB

Tel: **0116 454 1030**

Monday - Friday **9am - 1pm** then **2pm - 4pm**

## Coping with Cancer

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**Leicestershire and Rutland - providing emotional support to people with cancer, their families and friend. Includes support for ethnic communities and language lines. It also gives advice on legal matters.**

Tel: **0116 223 0055**

Language line: **0116 223 0020**

Website: **www.c-w-c.org.uk**

Monday-Friday **9.30am - 4.30pm**

## LOROS

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**Provides hospice and counselling services for Cancer and other terminal illnesses for over 18's.**

Groby Road, Leicester, LE3 9QE

Tel: **0116 231 3771**

Website: **www.loros.com**

## Cruise-Bereavement Care Helpline

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**Acts as a listening service for those who have been affected by a death. They provide information on practical and financial matters and details of support groups available.**

Tel: **0844 477 9400**

Website: **www.crusebereavementcare.org.uk**

## National Association of Funeral Directors

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**Can provide details of member funeral directors in your area.**

618 Warwick Road, Solihull,  
West Midlands, B91 1AA

Tel: **0845 230 1343**

Website: **www.nafd.org.uk**

## Heartline Association

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**For parents of children with heart disease - includes a bereavement group.**

Surrey Heath House, Knoll Road  
Camberley, GU15 3HH

Tel: **0127 670 7636**

Website: **www.heartline.org.uk**

## Macmillan Cancer Line

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Tel: **0808 808 2020**

Monday-Friday **9am - 9pm**

### Muslim Burial Council

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**There is an answer phone message which gives you a contact number for between the hours of 7:00am and 8:00pm if you need to make arrangements for a funeral. Out of these hours there is no one available however any Funeral Directors will be happy to advise you.**

Tel: **0116 273 0141**

Website: **[www.mbc.org.uk](http://www.mbc.org.uk)**

### The Samaritans

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**Are available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair.**

1a Elm Field Ave, Leicester, LE2 1RB

Tel: **0845 790 9090**

Website: **[www.samaritans.org.uk](http://www.samaritans.org.uk)**

### Registrar of Births, Marriages and Deaths

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The Town Hall Leicester,  
Bowling Green Street Entrance.

Tel: **0116 454 1000**

### Terrence Higgins Trust

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**For information, support and advice on HIV and sexual health.**

Tel: **0845 122 1200**

### The Laura Centre

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**Offers a range of services for anyone affected by the loss of a child. Also provides support for children and young adults affected by a death of a relative or significant other.**

4 Tower Street, Leicester, LE1 6WS

Tel: **0116 254 4341**

Website: **[www.thelauracentre.org](http://www.thelauracentre.org)**

### Winston's Wish

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**Telephone help and advice, especially for bereaved children and siblings.**

The Clara Burgess Centre,  
Gloucestershire Royal Hospital,  
Great Western Road, Gloucester, GL1 3NN

Family Line: **0845 203 0405**

Website: **[www.winstonswish.org.uk](http://www.winstonswish.org.uk)**

Monday - Friday

**9am - 5pm**

### Helpful books

**Fred** - By Posy Simmonds

**What on Earth Do You Do When Someone Dies?** - By Trevor Romain

**Beginnings and Endings and Lifetimes In-Between**

**I'll always love you**

By H. Wilhelm

**A Dragonfly Tale** - By Jacqui Grove

**Sad isn't Bad** - By Michaelene Mundy

**Gentle Willow** - By Joyce C. Mills

**I Miss You** - By Pat Thomas

**Where's Jess?** - By M. Johnson

**No Matter What** - By Debi Gliori

**Always and Forever** - By Alan Durant

Primary - School age children (and above)

**Water Bugs and Dragonflies**

By D. Stickney

**Charlotte's Webb** - By E.B.White

**Badger's Parting Gift** - By Susan Varley

**What's Heaven?** - By Maria Shriver

**The Frog who Longed for the Moon to Smile** - By Margaret Sunderland

**The Day the Sea went Out and Never Came Back** - By Margaret Sunderland

**Why Do People Die?**

By Cynthia MacGregor

**Freddie the Leaf** - By Leo Buscaglia

Early Teens

**A Summer to Die** - By Lois Lowry

### Glossary of Terms

**Burial** - The placing of the body in a grave.

**Coroner** - A public officer whose principle duty is to enquire into the cause of any death where it has been sudden, unexpected or where there is reason to suppose that it might not be due to natural causes.

**Cremation** - To reduce the body to ashes by burning.

**Cremation Form (Part A and Part B)** - 2 parts to the Cremation Certificate, which needs signing by two different Doctors.

**Death Certificate** - An official document issued by the Registrar of Births, Marriages and Deaths when the death is registered at the Register Office.

**Embalming** - Hygienic treatment for preservation and presentation purposes.

**Funeral Director (also called Undertaker)** - Somebody whose business is preparing the body for burial or cremation and arranging/managing funerals.

**GP** - Abbreviation for General practitioner or family Doctor.

**Medical Certificate of Cause of Death** - An official document issued by a doctor, stating the date, place and cause of a person's death.

**Post Mortem Examination** - An examination of the body after death to determine the cause of death.

**Registrar of Births, Marriages and Death** - A person who records of births, marriages and deaths.

## How to Contact the Diana Nurses On-Call

Contact the 'First Contact' identified at the front of the booklet.  
This is usually the ward your child attends or Rainbow's Hospice.



Wait for the On-Call Nurse to call you back.



Talk to the On-Call Nurse about what to do and whether you want them to  
visit you at home.



If you want a visit the On-Call nurse will contact another designated Professional to  
accompany her/him to your home. This is in adherence to the loan working policy of  
Leicester City PCT Children's Community Health Service.



If a visit is not required the On-Call nurse will provide support over the phone.

### → How to make a complaint, comment or suggestion

We welcome your complaints, comments and suggestions. These help us improve our service to you. If you are not satisfied with something we do, you can complain. You can make a complaint, comment or suggestion by speaking to the person providing your care or by:

✉ **Writing:** Complaints Team, Leicestershire Partnership NHS Trust,  
Room 170, Penn Lloyd Building, County Hall,  
Leicester LE3 8TB

☎ **Telephoning our Patient Liaison Manager:** 0116 225 6578

💻 **Completing a feedback form on our website:** [www.leicspt.nhs.uk](http://www.leicspt.nhs.uk)

@ **Email:** [feedback@leicspart.nhs.uk](mailto:feedback@leicspart.nhs.uk)

We investigate all complaints. If you provide your contact details, we will confirm receipt of your complaint within three working days. We will also discuss with you how we plan to investigate, how long the process is likely to take and how you want us to provide feedback.

Making a complaint will not prejudice the care we provide to you or anyone else involved. For more detailed information about how to complain, please contact our Patient Liaison Manager.

## Useful Notes:

## 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

Contact us if you would like this document in large print size 18 or 24 point font, in spoken word, printed or as a computer file.

**If you require help understanding this leaflet because it is in written English please telephone 0116 295 4743.**

এই ডকুমেন্ট'এর কোন বিষয় বুঝতে আপনার যদি সাহায্যের প্রয়োজন হয়, তাহলে অনুগ্রহ করে 0116 295 4743 নাম্বারে টেলিফোন করুন।

જો તમને આ દસ્તાવેજમાં આપેલ માહિતી સમજવા માટે મદદ જોઈતી હોય તો મહેરબાની કરીને **0116 2954743** પર ફોન કરો.

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