



Plan, prepare  
and *End Of Life* care



  
**GREENACRES™**  
**WOODLAND BURIALS**  
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**healthwatch**  
St Helens

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*'End Of Life Care' Booklet*

Plan, prepare  
and *End Of Life* care



**healthwatch**  
St Helens

# Plan, prepare and *End Of Life* care

## Introduction

The aim of this booklet is to ensure that:

***‘People in St. Helens are supported to live well before dying with peace and dignity in the place of their choice’.***

This pack has been created to provide people with information about End of Life (EoL) care for either themselves or a loved one they are supporting. In today’s society people have become more open about discussing final wishes. With this in mind, we have provided further information on what to consider when planning for the future.

By End of Life we mean when a person has reached the advanced stage of a progressive illness or condition, which may last days, months or even years.

Sometimes death can be sudden and unexpected.

**The pack is split into 3 sections:**

### **PART 1**

Approaching End of Life / Terminal Illness

### **PART 2**

Death at Home

### **PART 3**

The Period Following Death

# St Helens & Knowsley Citizens Charter for End of Life Care

Supporting the people we care for to live well before dying  
with peace and dignity in the place of their choice.

*You  
matter  
to us!*

## End of life care

- is the total care of a person with an advanced, progressive, incurable illness or frailty
  - is not just about dying
  - may last a few days, or for months or years
- begins when, and continues as long as, it is needed

### You should expect

to be supported with skilled, knowledgeable health and care professionals who can recognise that you are approaching the end of life and work together to co-ordinate and manage your care.



### You should expect

to be supported with trained staff, who will help you to think and plan ahead, if you want to, so as to be able to discuss your wishes and preferences for your care.

### You should expect

to have a regularly reviewed, plan for care individual to you and your needs, that includes decisions and actions in accordance with your needs and wishes.

### You should expect

with your agreement, that your plans, if you have made any, are shared with others involved in your care, so that your wishes may be fulfilled wherever possible.

### You should expect

to be helped to remain as independent as possible and supported with health and care staff who maintain your dignity and sense of control throughout the course of your illness.

### You should expect

the needs of your family and others identified as important to you to be respected and met, as far as possible.

### You should expect

the possibility that you may die within the next few days or hours will be recognised and communicated clearly and sensitively, to you and those who are important to you.



### You should expect

that, if you wish, those who are important to you are involved in decisions about your care and treatment.

### You should expect

a plan for care which includes food and drink, symptom control, psychological, social and spiritual support.

### You should expect

that you, and those important to you, will be treated with compassion and respect towards the end of life.

### You should expect

that during your illness and after your death, those important to you, receive practical, emotional and spiritual support.

### You should expect

that your body will be treated with dignity and respect after your death.

# PART I

## Approaching End of Life

### Emotional

#### Conversations with a loved one approaching the end of life (EoL)

Whether you have been diagnosed with a life-limiting illness or you are planning for the future, having a conversation with your loved ones can be a difficult and emotional one but it ensures that your wishes and preferences are carried out as you approach the end of your life. It will also help your family and loved ones with the organisation of your affairs and provide comfort in the knowledge that they have done their best for you.

People with neurological conditions such as MS (multiple sclerosis), MND (motor neurone disease) and Parkinson's Disease may wish to put down their wishes soon after diagnosis. These are progressive diseases but their end of life care can take from as little as weeks to years. The End of Life care will then happen at trigger points when the disease is in the 'active stage.'

The following suggestions may help:

Set time aside in a place where you will not be disturbed.

- Booklets may help you introduce this discussion and be a focal point for support such as **'Preferred Priorities of Care'** or **Lifebook**.
- Make notes beforehand if it helps.
- Be honest about how you feel even though it may upset your loved ones.
- Take your time with this process – it may need several conversations, especially as it is a difficult, emotional topic.
- For those people who have no family or loved ones, they can talk to a spiritual/religious leader such as a vicar/priest and/or health professional about their wishes. This can be documented in any of the of the following:

**Preferred Priorities for Care** is a booklet which you can complete to record how and where you wish to be cared for and any changes you may make about what's important to you. This is not a document to state your refusal for any particular medical treatment. This should be discussed with your doctor. More information is available on the NHS website.

**Age UK LifeBook** is a booklet which helps you to record any useful details, contacts and where your important documents can be found, using step-by-step instructions. More information is available on the Age UK website or visit the Age UK Information Office in Cloughton Street, St Helens.

## Practical

**Advanced Care Planning** is a specific form of End of Life care planning. It means thinking about how you would like to be cared for in the future if you lose the ability to make decisions for yourself. Advanced Care Planning includes:

- **Advanced Decisions to Refuse Treatment (ADRT)**

Should you wish to refuse medical treatment discuss your options with your doctor first. Your wishes will be laid down in a legal document providing you are over 18 and have the mental capacity to make the decision. The document needs to be signed and witnessed.

- **Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)**

Survival rates for heart attacks or failures are not as high as portrayed in the media. A person may have strong views particularly if DNACPR enables them to die with dignity. Again this decision is achieved with mutual consent between patient and medical staff and the family need to be involved. DNACPR is a lilac form and when completed it remains the property of the individual.

- **Care and Communication Record**

The Care and Communication Record is simply a care plan for all involved to improve the patient and family care at the end of life.

This document is put into place when it is recognised that a person may be entering the last few hours or days of life, and it is initiated by a **GP** and a **District Nurse** or **Palliative Care Team** in the community or the equivalent within the hospital.

It is used across the community; this includes care homes and the person's own home, within the hospice and in hospital.

In some cases the GP or Medical Professional would refer the patient to the hospice for symptom control or End of Life care if it is in the best interests for all around.

- **Aids and Adaptations**

A wide range of mobility and care products are available at discounted prices – a minimum of 20% reduction and for hire for people with a terminal illness. If products are bought they can be donated back to an Independent Living Store. In some cases the product may be bought back at a reduced price depending on what it is.

## Lasting Power of Attorney (LPOA)

This allows you to give someone you trust the authority to act on your behalf if you find yourself in a position where you are unable to or do not want to make decisions about your finances and property, plus health and social care needs. In other words – **lacks mental capacity**.

**You will need two separate LPOAs for this:**

- **One for Finance and Property**
- **One for Health and Welfare**

This can be done by filling a form on-line but again you may want a solicitor to draw one up for you. You will have to pay a fee for each to be registered at the Office of Public Guardian.

If there is no Power of Attorney and you lose the ability to make decisions, your family or loved one or even a social worker will have to apply to the Court of Protection which then makes the decisions or appoint a solicitor to do so. This is expensive and time-consuming. A list of St Helens solicitors can be found in 'Yellow Pages' or on-line. Age UK also have factsheets which you can access at their information office in Cloughton Street.

**End of Life Care Planning** involves looking at issues across areas of your life that are particularly significant as you reach end of life.

- **Making a Will**

A will gives clear instructions about who you want your money and property to go to; otherwise your estate may unwittingly go to different people. There are 'do-it-yourself' wills which are fine for straightforward cases but a solicitor is recommended for more complex cases. If you already have a will made from a long time ago, you may want to review and change it.

There is a 'Free Wills Network' where solicitors partner with charities in the network who offer a free will-writing service in return for a percentage of the estate plus VAT, such as the Stroke Association, Cancer Research UK and Oxfam. This service is mainly offered to the over 55s, and March and October are usually 'free wills month'.

Not leaving a will could cause problems where your estate could be frozen for years.

- **Taking Care of your Pets**

If you have pets you may want to think about what you want to happen for them.

- **The Cinnamon Trust** is a charity for older people and their pets. They have volunteers to take your pet for walks or take in to foster if you have a short stay in hospital. They have a register of homes which will take in pets and a life-time care package for your pet when you die. These homes are thoroughly vetted and put on a Pet friendly Care Home register.

- **The Dogs Trust** also take in pets when they can no longer be cared for and look after them until they are re-homed. They are never put down.

## Religious / Spiritual Needs

You may wish to discuss your religious, spiritual or other values, beliefs and needs, leading up to the end of life, and after death, and also discuss how you want them to be carried out. This can include the use of rituals, talking and getting support from a specific person, such as a vicar, priest, spiritual leader or someone who shares your beliefs about the approach to the end of life and how to cope with it. You may wish to discuss your funeral.

## Funeral Planning

It may be worth considering writing down your own final wishes if you feel you are able to. The type of service and wake/celebration needs to be considered. You may wish to include poetry, hymns, and prayers relevant to you. It may be an idea to write a short story about you and your life, which is suitable to be read out.

If you are religious make sure you say which place of worship you attend. If you have no faith or you are unsure, you could consider a non-religious or humanist funeral.

**By UK law the death must be certified and registered and the body properly taken care of either by burial or cremation.**

You will need to decide whether to be buried or cremated, and you may want a particular place for burial of the ashes or scattering of the ashes. You will have to buy the plot beforehand or use an existing grave which could be a family plot. If you are going to use an existing grave you will need to contact the person who holds the deeds to the grave and get their agreement. You will also need to check with the **cemetery** if there is room in the existing grave. The deed holder has exclusive right of burial but if the deed holder is deceased then it is usually the next of kin who is the holder of the deeds.

If the existing grave has a headstone which needs removing for the burial and engravings to be inscribed the cemetery will need to be contacted to give permission to allow the **stonemason** into the cemetery.

There is a charge for this which currently stands at £52.

However, when planning your funeral you may want to consider the list:

- **Who will be leading the service?**

Church representative – Celebrant – Humanist – Interfaith Minister

- **Type of Coffin**

Veneer – Wood – Wicker – Bamboo – Cardboard

- **Funeral Service**

Choice of songs – Poetry – Readings – Life-story to be read out – Flowers – Dress code of guests

- **Wake at location of your choice**

- **Disposal of the Body**

Burial or cremation (as required by law)

Burial plot – this is if you wish to be buried or your ashes from cremation to be buried

Location for scattering of the ashes if cremation of the body is chosen

Taking steps to plan your own funeral can make it easier for those people who are left to manage it after your death. It will be even easier if this is written down.

If you do not make decisions in the planning of your own funeral then someone will have to decide for you after your death – including the ceremony and whether you are buried or cremated.

It can be difficult to organise a funeral for those who are left behind to do the planning, especially if they are unsure of your wishes. It can be doubly difficult if the person organising the funeral is a loved one.

**No Funeral Plan** – If the deceased has not left any final wishes nor made any decisions for you to follow, it may be easier to share the task with a relative or close friend, but asking what they think they would have liked if they have not been able to leave final wishes for you to follow.

One question asked by a **Funeral Director** will be 'were they religious?'

Perhaps you know of a place of worship in which they attended. If they were of no faith or you are unsure you could consider either a celebration or humanist.

If a cremation is chosen you will then need to decide whether you would like an ash scattering, burial or ashes plot. It may be the case that you decide to keep the ashes for a while until you make up your mind or your loved one already has a family grave. Bear in mind you will need to contact the deed holder as stated above, and also the cemetery.

**GreenAcres Woodland Burial Trust** offers burials, ash scatterings, and ashes plots, in either an orchard or woodland setting.

- Standard coffins are allowed
- Embalmed bodies are allowed
- Memorials are allowed but need to be made of wood

## Funeral Directors

There are a wide range of Funeral Directors (undertakers) to choose from when the time comes, from family run independents, to the Co-operative Funeralcare and Dignity Group. All have their own pricing structure and offer slightly different services.

Make sure you outline what it is you want. Funeral directors are there to help and will accommodate your wishes as far as reasonably possible.



## **By UK law the death must be certified and registered and the body properly taken care of either by burial or cremation.**

Funerals are expensive and as such many choose to take out a funeral plan. Please ensure you are fully aware of what you will and will not get when your plan has to be put into effect.

### **St Helens Council's Partnership Funeral Service**

As part of St Helens Council's Partnership Funeral Service, anyone arranging the funeral service of a loved one who was a resident of the borough can now benefit from an improved service by four local, well-established and reputable Funeral Directors.

Prices start from £1,397 - £1,775 based on a cremation or burial in an existing grave and this cost is available to all residents of the borough and not related in any way to your income.

Houghtons Funeral Service, Co-operative Funeral Care, Haydock Funeral Service Ltd and Kane Funeral Service will provide a cremation at St Helens Crematorium or burials at St Helens or Newton Cemeteries – arranged to the same high standard as any other funeral arranged by the company of choice.

This includes:

- Collection of the deceased within the borough's boundaries (during business hours)
- Provision of the Chapel of Rest (during business hours)
- All arrangements for a dignified funeral at the crematorium or cemetery
- Suitable coffin with appropriate fittings
- Motor-hearse and one following limousine
- Crematorium/Cemetery charges at St Helens Crematorium or St Helens/Newton-le-Willows Council Cemeteries
- Medical referee fee
- Clergy/Officiate and all medical fees

Burials and Services in a private churchyard or additional services are also available, although additional fees will apply.

If you wish to take advantage of this service, please call the funeral director of your choice on the numbers below at any time. They all offer a 24-hour service and quote the partnership funeral service arrangement.

- **Houghtons Funeral Service**, 4 Station Road, Great Sankey, Warrington WA5 1RQ  
**Tel: 01925 729998**
- **Houghtons Funeral Service**, 216 Lovely Lane, Warrington WA5 1QF  
**Tel: 01925 245555**
- **Co-operative Funeral Care**, 3-5 Eccleston Street, St. Helens WA10 2PF  
**Tel: 01744 23675**
- **Co-operative Funeral Care**, 238 Crow Lane East, Newton-le-Willows WA12 9UA  
**Tel: 01925 226257**
- **Haydock Funeral Service Ltd**, Coniston House, 315-317 Clipsley Lane, Haydock WA11 0SG  
**Tel: 01744 606200**
- **Kane Funeral Service**, 23 Peckers Hill Road, Sutton, St Helens WA95LQ  
**Tel: 01744 302858**

For further information or advice concerning any aspects not included in the Partnership Service, please contact a member of the Bereavement Services Team by calling 01744 677406/7, Monday-Thursday 9.00am-5.00pm, Friday 9.00am-4.30pm, or visit St Helens Council website.

## Contact Details

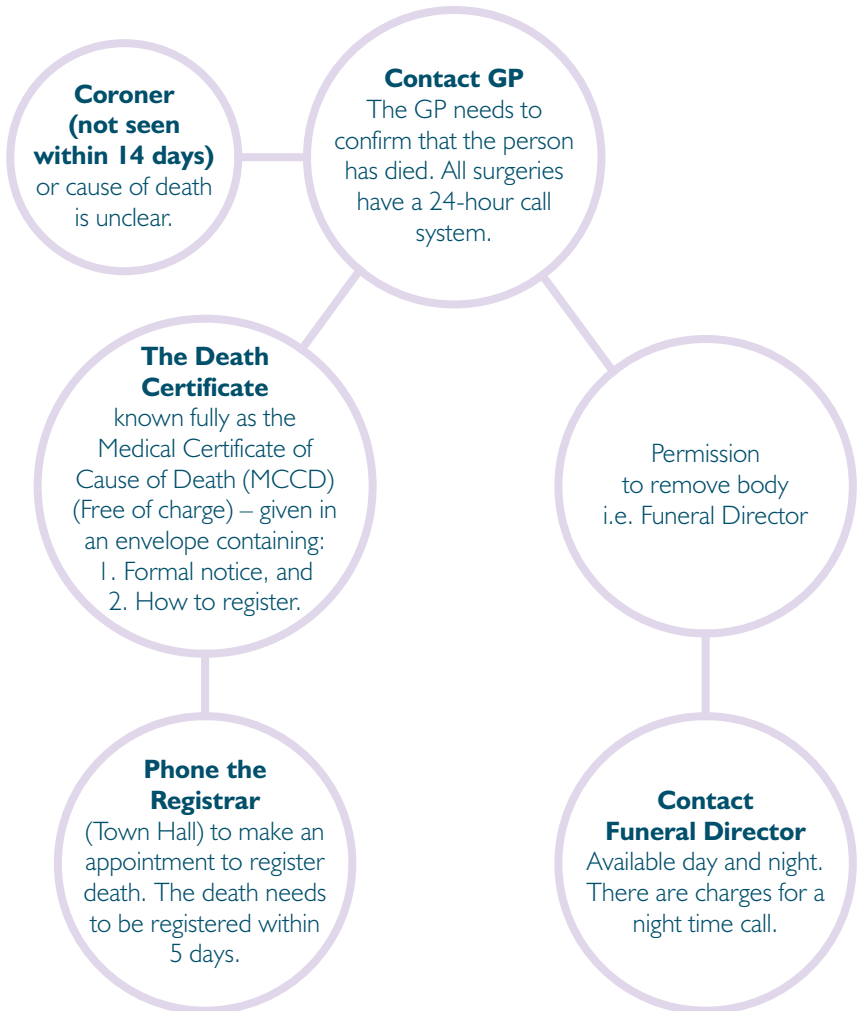
- **St Helens Council Website** [www.sthelens.gov.uk/funerals](http://www.sthelens.gov.uk/funerals)
- **St Helens Cemetery & Crematorium**, Rainford Road, St Helens WA10 6DF  
**Tel: 01744 677407**  
Full details including fees and charges are on the website:  
[www.sthelens.gov.uk/a-z-services/c/cemeteries](http://www.sthelens.gov.uk/a-z-services/c/cemeteries)
- **GreenAcres Woodland Burials**, Blindfoot Road, Rainford, Merseyside WA11 7HX  
**Tel: 01744 64918**  
Full details including fees and charges are on the website:  
[www.greenacreswoodlandburials.co.uk/rainford](http://www.greenacreswoodlandburials.co.uk/rainford)
- **Independent Living Store**, St Mary's Arcade, St Helens WA10 1AR  
**Tel: 01744 607379**
- **Ableworld**, 9, Eccleston Street, St Helens WA10 2PG  
**Tel: 01744 453038**  
[www.ableworld.co.uk](http://www.ableworld.co.uk)  
Email: [info@ableworldsthelens.co.uk](mailto:info@ableworldsthelens.co.uk)
- **Cinnamon Trust**  
**Tel: 01736 757900**  
[www.cinnamonTrust.org.uk](http://www.cinnamonTrust.org.uk)
- **Dogs Trust**, Whiston Lane, Huyton, Liverpool L36 6HP  
**Tel: 0151 480 0660**  
[www.dogstrust.org.uk](http://www.dogstrust.org.uk)
- **Age UK Mid-Mersey Information and Advice Service**, 24, Cloughton Street, St Helens WA10 1RZ  
**Tel: 01744 752644**  
[www.ageuk.org.uk](http://www.ageuk.org.uk)  
Email: [enquiries@ageukmm.org.uk](mailto:enquiries@ageukmm.org.uk)
- **MS Society (neurological conditions)**  
Tel: 02088270217  
[www.mssociety.org.uk](http://www.mssociety.org.uk)
- **Office of the Public Guardian (England and Wales)**  
**Tel: 0300 456 0300**  
**Textphone: 0115 934 2778**  
[www.justice.gov.uk/about/opg](http://www.justice.gov.uk/about/opg)

## PART 2

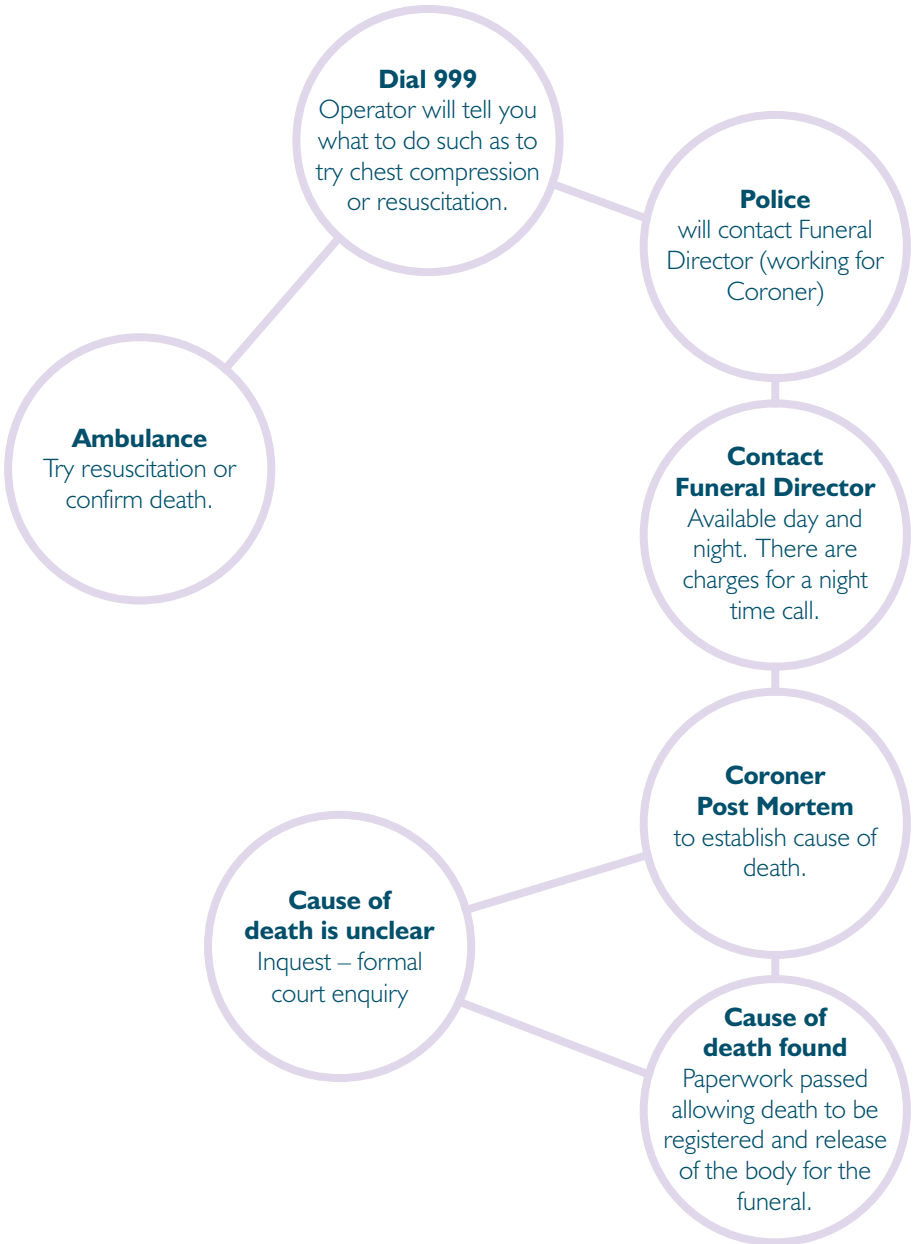
# Death at Home

### Flowcharts for Death at Home

A simple flowchart for you to follow if death was **EXPECTED** and the person was seen by a doctor within 14 days.



**A simple flowchart for you to follow if death was UNEXPECTED.**



## Palliative Care

Palliative care aims to achieve the best quality of life for people with a life limiting illness. For people with progressively deteriorating conditions such as MS and in some cases cancer, palliative care can occur at certain trigger points over a long period of time. For others palliative care can be short, when the illness is advancing quickly. Palliative care is designed to make your life more comfortable involving a team of health professionals who make up the **Palliative Care Team (PCT)**. They work across the hospital, home and hospice. This includes your GP, clinicians and nurses.

Most people choose to die at home surrounded by loved ones, and knowing your wishes your medical team will do their best to make it happen. However this choice may not be possible as the illness progresses which results in admission to hospital or a hospice.

**The information below focuses upon 'Death at Home.'**

## Signs Someone is Dying

Signs that someone is dying can vary from one person to the next. Generally there is a reduced need to eat and drink but hydration around the lips can help them to be more comfortable. The skin can become very pale, moist, almost waxy and cool prior to death.

Being with the person, holding their hand may be comforting for them or they may not be aware but may still be able to hear you. Lack of interest in the surroundings is natural and might be accompanied by feelings of tranquillity. This is not a snub to the loved ones present.

The person can become sleepier or more restless. Restlessness may be helped by medication provided by a medical professional. Breathing can change from being a rattling noise to shallow breathing until there is a sense of the patient withdrawing from the world and eventually lapsing into a state of unconsciousness.

## Immediate Reaction After Death

If at home, you may be a little unsure at first and might try to wake them up. Reactions can vary from howling and sobbing to a sudden relief or disbelief. Others who may have had plenty of preparation for the final moment might accept the time has come.

## What Next?

If the death occurs in a care home the staff will contact the next of kin and the GP. If your loved one has lived in a care home and lacks capacity it may be necessary for the **Police** to be involved and the **Coroner** due to a law around **'Deprivation of Liberty' (DoLs)**.

If the death occurs in the hospital you may be offered a choice of having a lock of hair from your loved one or you could ask the hospital staff.

The hospital mortuary will keep the body until the executor makes arrangements for the body to be taken away.

The hospital doctor will give:

- **A death certificate** in a sealed envelope addressed to the **Registrar of Births, Deaths and Marriages**
- A notice explaining how to register the death

**If the person dies at home** suddenly, ring the **GP's surgery**. If death takes place during the night your phone call will be automatically transferred to an **'Out of Hours' (OOH) service called ROTA which is staffed by doctors. The doctor** will come to attend the body of the deceased, and contact the Police who will contact the Coroner.

**If the person dies at home and it is expected**, then you can contact the **GP's surgery** but may be told that because the death is expected and the deceased has been seen in the previous 14 days – to contact the **Funeral Director** directly.

Ring the **Funeral Director** chosen by the deceased person during the planning stage. If they did not appoint one there are lists of them on the internet, or in directories such as **Yellow Pages**. Once the funeral director or undertaker is contacted then they will come to the house and take the body of the deceased away.

- **The Coroner** is an independent judicial officer under the Ministry of Justice, and is located regionally. Coroners are appointed and paid by whichever local authority area requesting the investigation. St. Helens cases are investigated by the Liverpool or Southport Coroner. In a small number of cases they are responsible for investigating a sudden death, an unclear death, a death through violent circumstances including suicide, death during an operation, recovery from an anaesthetic, or death by industrial accident/poisoning. Such circumstances are usually reported by the police or GP and sometimes the registrar. In addition, if the deceased was not seen by a doctor within the 14 days prior to death, then this must also be reported to the coroner.
- **The Registrar of Births, Marriages and Deaths** is employed by the Local Authority and issues the death certificate. The death needs to be registered within 5 days of it happening. There is an appointment system so you will need to phone for a date and time to register the death. If there is a post mortem, the Coroner's office will advise you.
- **Registry Office**, Central Street, St Helens WA10 1UJ  
**Tel: 01744 676789**  
[www.sthelens.gov.uk](http://www.sthelens.gov.uk)  
Email: [registryoffice@sthelens.gov.uk](mailto:registryoffice@sthelens.gov.uk)

**If the person has died at Whiston Hospital then you need to register at the Prescot Registry Office which is under Knowsley Council.**

- **Knowsley Registry Office**, High Street, Prescot L34 3LD  
**Tel: 0151 443 2900**  
[www.knowsley.gov.uk](http://www.knowsley.gov.uk)  
Email: [registrars@knowsley.gov.uk](mailto:registrars@knowsley.gov.uk)

# Death of a Child

## Expected Death

In the case of the tragic experience of losing a child, through a long-term illness or life-limiting condition where death is expected, there is likely to be a team of professionals already supporting parents with an appropriate care pathway in place.

Such professionals will work with the family and loved ones to give support.

In these circumstances, the Coroner may need to order a post-mortem, but otherwise the death can be registered quickly and funeral arrangements proceeded with.

## Sudden Death

This will involve the Police and hospital professionals such as a paediatrician. They will ask questions about what happened and information about the child. In the case of a death at home such as a cot death, the Police will ask questions to rule out any possible foul play.

Any unexpected child death starts a rapid response. This means the child will be taken to A&E department **straightaway** and examined by the Paediatrician. Blood and other tissue samples may be taken. Parents or loved ones should be offered an opportunity to have a lock of hair or hand and footprints of the child.

Within the **first week** a post mortem is then carried out to establish a medical explanation for the death, to identify other conditions which may be important to the family or help to prevent the same thing happening to other children in the future.

A final case discussion takes place amongst the team of professionals who have been involved and a report produced. The Coroner decides whether to hold an inquest. This may take anything from 1 week to a few months depending on whether any more information is needed surrounding the child's death. This is not about blaming anyone for the child's death.

It is important that the parents are kept informed at all stages of the review into their child's death.

## PART 3

# The Period Following Death

### Emotional

#### Stages of Grief

There is no timescale as to when you 'get over' a loved one's death. There may be no 'getting over it' but a final acceptance. To grieve is a healthy process and different cultures have different rituals. Everyone grieves differently and you need to find the way that works for you. Generally the stages of grief are as follows and you may experience:

- **Disbelief** – you may feel numb with shock and it seems surreal in that the death has not really happened.
- **Sadness** – and anxiety, maybe guilt, a sense there is no future.
- **Anger** – at being left, and anger at others who don't feel the same way as you.
- **Acceptance** – that the person has died but that does not stop you missing them. You may feel guilty when ready to move on.

There may be a physical reaction such as lack of appetite, not sleeping. Dreaming of the person is common, even seeing them in the physical sense such as being convinced that you have seen them walking down the street.

A close relationship with the loved one even though it may have been fraught at times can lead to a sense of emptiness and isolation after their death.

It helps to:

- Cry – try not to hold back on feelings. Crying can help to release the grief, even though the feelings may remain for a long time.
- Keeping in touch with friends and family, or someone who supports and cares for you can be important. Although they may not know what to do or say, don't cut them off as keeping in touch reduces the sense of isolation you may be feeling.
- Try not to make long term important decisions at such an emotional time, such as moving house. If possible leave it for a year before considering this.
- Take good care of yourself – plenty of rest and sleep, and try to maintain a good healthy diet. Going out in the fresh air can be calming. Be kind to yourself – do things that make you feel good about yourself.
- Talk to someone – this could be a vicar, priest, friend or a support group. Sometimes it is easier to talk to someone outside the family. Make sure you are getting the support you need.

#### Talking to a Child About Dying and Death

The important thing is to not avoid the subject as it is a natural process of life. We cannot protect children from it as it will happen all around them throughout their lives. By the age of 8 many children understand that death is permanent. Talking to children about dying beforehand can help them be more understanding when someone close or a family pet dies. Myths and unanswered questions can lead to fears about death, so it is important to acknowledge a child's sadness and answer their questions honestly, even if



the answer is simply that you don't know. Telling a child that a person has 'gone to sleep' implies that the person will come back leading to false hopes and expectations.

It is an idea to introduce death as part of a life's cycle such as the seasons and nature and human beings are part of that. Tell children about the ritual of burial and allow them to be part of that so they are given a chance to say goodbye. Memory boxes are a good way to help with the grieving process.

When there is a death of someone close to the child, it will help to notify the school.

There are many books about dying which are catered for children which can be ordered from Winston's Wish. The following contacts are for families and children who have lost a child /brother or sister.

## Key Points when Supporting Someone Who is Bereaved

### What to say or do:

- Use the word **'has died'** or **'is dead'** as it indicates it's a permanent state. The deceased is never coming back
- Say 'I'm sorry to hear about...'
- Say 'I've been thinking about you...'
- Show you care by offering support – 'I am here for you' but don't be an unwelcome presence
- Talk about a happy memory of the loved one
- Say 'I don't know how you feel but you might want to tell me...'
- Being there and being silent is OK
- Treat the bereaved person the way you have always done

### What not to say or do:

- Using words such as 'lost' or 'gone to sleep' indicates temporary states and indicate (especially to children) that they may come back or might lead to them becoming fearful of sleeping
- 'I know how you feel...' because you don't know
- 'You'll get over it...' because they won't but they will learn that life goes on but that it will be different
- Don't put time limits on the grieving period
- Use clichés that such as – 'Time is a great healer...', 'It's for the best...' 'It's meant to be...'. They don't sound genuine
- Don't try and 'fix' the bereaved person, as it minimises their grief
- Never avoid the bereaved person

## Practical

When someone dies there are certain decisions and arrangements to be made. It will be useful to have the following information to hand to complete any necessary forms:

- National Insurance number
- NHS number
- Date and place of birth
- Date of marriage or civil partnership if applicable
- Child benefit number if applicable
- Tax reference number

- Passport
- Driving licence
- Proof of address of the deceased such as utility bill

### **What to do in the first five days:**

- Notify the family doctor (should be involved already if the person has died at home)
- Register the death within 5 days at the registrar office in St Helens or Prescot (except where the death is referred to the Coroner). You will need to make an appointment for this. Here you will receive the death certificate.

This is important for cancellations of accounts, benefits, income and services used by the deceased. It may be helpful to have several photocopies of the death certificate.

The registrar will give you a form GRO21 which permits the burial or cremation of the deceased. Form 36 is given to you by the Registrar to produce at the Social Security Office if the deceased was claiming benefits.

[www.gov.uk/govtuploads](http://www.gov.uk/govtuploads) or contact the benefits office.

- Begin funeral arrangements via a funeral director (who might be chosen already) and note special requests by the deceased.
- Notify family and friends.

If you are the person who is arranging the funeral and claiming benefits, you may be able to apply for a **Social Fund** towards the cost of the funeral.

**Citizens' Advice St Helens** can help those in financial hardship to apply to the British Gas Energy Trust for grants to assist with funeral expenses. You do not have to be a customer of British Gas to apply.

### **Later on:**

**The Will of the Deceased** – This will name the Executor of the will or contact the Executor if you know who it is. They can begin the legal process of applying for probate so the estate can be administered. If there is no will, the process of probate can be complex and lengthy.

If you cannot find the will contact the solicitor.

Once probate is through then the estate is distributed to the named beneficiary(ies) in the will. The beneficiary(ies) may be family, friends, loved ones or others.

**'Tell Us Once' Service** – St Helens Council offer this simple service to help you inform all the relevant services within **St Helens Council at one go**. These include the following:

Adult Services, Children's Services, Blue badge, Electoral Services, libraries, housing, housing benefit, council tax, finance.

Also the Council will notify other **Government Agencies** such as:

Identity and Passport services, Driving and Vehicle Licensing Agency (DVLA), Department for work & Pensions (DWP), HM Revenue & Customs (HMRC), Merseytravel, NHS Equipment Store, Helena Housing.

You will need to make a **'Tell Us Once'** appointment and bring the relevant paperwork or items from the list above including the death certificate which they can be photocopy, and any borrowed books, CDs from the library.

Contact the **Tell Us Once** team at the Council.

## Finance

If your loved one is your spouse or civil partner, you may be entitled to benefits including a lump sum bereavement payment, based on whether spouse / civil partner paid National Insurance (NI) contributions. If under state pension age and over 45 with no dependent children you may be entitled to bereavement allowance paid up to a year. If you have dependent children you may be entitled to Widowed Parent's allowance.

- There are new rules regarding state pensions being brought out in April 2016. The Department for Work and Pensions Service carries out eligibility checks on surviving relatives to see what benefits you could be entitled to. They also take claims for bereavement benefits and Funeral Payments.
- Please note that this section is only brief as there are so many changes regarding benefits, pensions and lump sum payments for relatives of the deceased. For information please refer to:

Age UK who also have extensive factsheets and there is an Information Support Officer based in Cloughton Street.

### **Notify the bank and utilities regarding the accounts of the deceased.**

**Stopping junk mail to the recently deceased** – A free service via Bereavement Support Network  
– To register for this service simply go online.

## Other Practical Support

If you have been a Carer and not been able to work, there will probably be a feeling of a void in your life despite the stresses of being a Carer. The Carers Centre will provide emotional support even though you are no longer caring for someone. They can help you get your life back on track by helping you in a practical sense such as providing information on how to go about claiming benefits before being ready to enter the world of work. There may be financial support in helping to pay for utility bills.

# Useful Contacts and Websites both locally and nationally

## Bereavement Support for Children and Families

### **Child Bereavement UK,**

Suite 1, Victoria Buildings, High Street, Runcorn, Cheshire WA7 1QS

Tel: 01928 577164

[www.childbereavementuk.org](http://www.childbereavementuk.org)

### **Jensons Twinkle Stars** – also known as S.T.A.R.S

167 Elephant Lane, St Helens, Merseyside WA9 5EN

[www.jensontwinklestars.co.uk](http://www.jensontwinklestars.co.uk)

### **Winston's Wish**

(also provides books and resources for children to understand and cope with the death of a sibling.)

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

### **Child Death Helpline**

Tel: 0800 282 986 and 0800 800 6019

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

## Bereavement Support for Adults

### **St Helens Bereavement Service,** 4th Floor, Tontine House, St Helens WA10 1BD

Tel: 01744 451793

### **Chrysalis Centre for Change,** Peter St Community Centre, Peter Street, St Helens WA10 2EQ

Tel: 01744 451309

[www.chrysaliscentreforchange.co.uk](http://www.chrysaliscentreforchange.co.uk)

### **Philippi Trust St Helens Counselling Centre,** 63 Park Road, St Helens WA9 1DS

Tel: 01744 602608

[www.philippitrust.com](http://www.philippitrust.com)

Email: [admin@philippi.co.uk](mailto:admin@philippi.co.uk)

### **Age UK Mid Mersey Trust Matters Counselling Service**

The Mansion House, Victoria Park, City Road, St Helens WA10 2UE

Tel: 01744 752644

[www.ageuk.org.uk](http://www.ageuk.org.uk)

[www.themansionhouse.org.uk](http://www.themansionhouse.org.uk)

### **Survivors of Bereavement by Suicide (SOBS)**

Liverpool Group

Tel: 0151 652 9089

[www.uk-sobs.org.uk](http://www.uk-sobs.org.uk)

Email: [sobs.admin@care4free.net](mailto:sobs.admin@care4free.net)

### **The Samaritans for Warrington, Halton and St Helens**

46 Arpley St, Warrington WA1 1LX

Tel: 01925 235000

[www.samaritans.org](http://www.samaritans.org)

**Carers Centre**, 31-35 Baldwin Street, St Helens WA10 2RS

Tel: 01744 675615

[www.sthelenscarers.org.uk](http://www.sthelenscarers.org.uk)

### **Crossroads for Carers**

A referral is required by a Health / Social Care Professional such as a District Nurse or Social Worker.

Tel: 01744 612499

[www.crossroads.org.uk](http://www.crossroads.org.uk)

Email: [sthelens.district@crossroads.org.uk](mailto:sthelens.district@crossroads.org.uk)

**St Helens ROTA**, Albion St Clinic, St Helens WA10 2HA

Tel: 01744 673801

[www.sthelensrota.com](http://www.sthelensrota.com)

### **St Helens Mindmatters – (Improved Access to Psychological Therapies)**

For short-term psychological interventions for people who experience common mental problems but cannot provide urgent /emergency service.

Tel: 01744 647100 (Mon-Fri 8am-8pm; Sat 8am-12pm)

[www.lancashirecare.nhs.uk/Mindsmatter](http://www.lancashirecare.nhs.uk/Mindsmatter) for on-line referral form.

### **For immediate NHS support call 111**

#### **The National Council for Palliative Care**

[www.npc.org.uk](http://www.npc.org.uk)

#### **Dying Matters**

Raising awareness of dying, death and bereavement and how to cope.

[www.dyingmatters.org](http://www.dyingmatters.org)

**National Health Service website:** [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

**Jobcentre Plus**, Gregson House, 2 Central Street, St Helens WA10 1UF

Tel: 03456 043719

[www.jobcentreguide.co.uk](http://www.jobcentreguide.co.uk)

[www.jobsearch.direct.gov.uk](http://www.jobsearch.direct.gov.uk)

**Tell Us Once Team**, Customer Services, Wesley House, Corporation Street, St Helens WA10 1HF

Tel: 01744 676789

[www.sthelens.gov.uk](http://www.sthelens.gov.uk)

Email: [contactcentre@sthelens.gov.uk](mailto:contactcentre@sthelens.gov.uk)

**The Contact Centre**, Wesley House, Corporation Street, St Helens WA10 1HF

Tel: 01744 676666

[www.sthelens.gov.uk](http://www.sthelens.gov.uk)

**Citizens' Advice St Helens**, The Millennium Centre, Corporation Street, St Helens WA10 1HJ

Tel: 01744 751 380

[www.sthelenscab.org.uk](http://www.sthelenscab.org.uk)

#### **St Helens Gateway**

A community hub of information on health and social care in St Helens.

[www.sthelensgateway.info](http://www.sthelensgateway.info)

#### **Department for Work and Pensions Bereavement Service**

Tel: 0345 606 0265

[www.gov.uk/dwp](http://www.gov.uk/dwp)

#### **Stopping Junk Mail**

[www.bereavementsupport.co.uk](http://www.bereavementsupport.co.uk).

[www.stopmail.co.uk](http://www.stopmail.co.uk)

## Trading Standards – St Helens

Tel: 01744 676488

[www.sthelens.gov.uk/what-we-do/business-support-and-licensing/trading-standards/scams](http://www.sthelens.gov.uk/what-we-do/business-support-and-licensing/trading-standards/scams)

Email: [tradingstandards@sthelens.gov.uk](mailto:tradingstandards@sthelens.gov.uk)

## Age UK Mid-Mersey

Information and Advice Service, 24, Claughton Street, St Helens WA10 1RZ

Tel: 01744 752644

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Email: [enquiries@ageukmm.org.uk](mailto:enquiries@ageukmm.org.uk)

## Glossary

**Coroner** – An independent judicial office holder who investigates the deaths that have been reported as either unnatural or violent.

**Deprivation of Liberty (DoLs)** – A law that is part of the Mental Capacity Act 2005. The aim is to make sure that people in care homes, hospitals and supported living are cared for in a way that does not limit their freedom.

**I.C.E – in case of emergency.** This refers to the contact person and phone number stored in your mobile phone should have an accident out in public. Whoever finds you can look up the I.C.E contact person on your phone.

**Inquest** – is a legal investigation to establish the circumstances surrounding a person's death, including how, why and when the person died. This is carried out in court.

**Lasting Power of Attorney (LPA)** – a legal document that lets you appoint a person – known as an attorney – to help you make decisions should you ever reach the stage where you lack mental capacity.

**Mental Capacity Act (MCA)** – A law that protects people who may not be able to make decisions such as people with dementia, a disability or a mental health problem.

**Palliative Care Team (PCT)** – A team of health and medical professionals to oversee end of life care as being comfortable and meeting the wishes of the patient as far as possible.

**Pathologist** – A doctor who specialises in understanding the nature and cause of death.

**Post Mortem** – Also known as an autopsy. The aim of the post mortem is to find out the cause of death. This is carried out by a Pathologist.

**Probate** – is a court process to decide to prove that a will is true to the deceased wishes, or the deceased does not leave a will. This is known as **intestate**.

**Resuscitation (also known as CPR – cardiopulmonary resuscitation)** is to bring back to life someone whose heart and breathing have stopped by using first aid techniques.

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**For our marketing purposes please tell us if you found this booklet useful by contacting us below:**

**Healthwatch St Helens**

**Tontine House**

**Church Street**

**St Helens**

**WA10 1BD**

**Tel: 0300 111 0007**

**[www.healthwatchsthelens.co.uk](http://www.healthwatchsthelens.co.uk)**

**Email: [info@healthwatchsthelens.co.uk](mailto:info@healthwatchsthelens.co.uk)**

Disclaimer: Information contained within the booklet was correct at time of print. April 2016

