



Care during the last days of life

A guide for patients and their carers



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Christie website

For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centre at Withington, Oldham or Salford.

Introduction

The aim of this booklet is to provide information on the care and support available for those approaching end of life.

It is important that your loved one receives the best care possible. We want to ensure comfort, peace and dignity, especially at the end of life.

This booklet contains information about the signs and symptoms that may be experienced by patients.

It will also outline the different services and teams we have here at The Christie, and what we can offer in terms of support at this very difficult time.

We appreciate that everyone is an individual and will have different needs. We hope that having some idea of what to expect and what is available may bring some comfort at a very difficult time.

There is also a section for you to write down any questions or any feelings or thoughts you may wish to share with us.

Supportive care team

We are here to offer emotional and psychological support and will be there to help you through your difficult time as much or little as you would like.

To access our service just ask the nursing staff on the ward to arrange a referral and we will be in contact usually within 24 hours.

Common symptoms

When someone is reaching the end of their life, some common signs and symptoms can start to present themselves. We strive to manage these symptoms to ensure a patient's last days are as comfortable and as peaceful as they can possibly be.

Knowing what to expect may ease your mind, and reassure you that certain signs and symptoms are completely natural. Below are some symptoms your loved one may experience.

Changes in breathing

When someone is in the last days of life chest secretions may build up. Breathing may change and become noisy. This does not cause discomfort to the person, but can be distressing for those around to hear. Medication can help ease this sound. As the body slows down the pattern of breathing may change and become either fast, shallow or deep.

Agitation

As part of the dying process patients may become agitated and restless. It is our constant aim to control and ease any signs of distress. We will make it our priority to ensure your loved one is settled and comfortable.

Pain

Your loved one may, or may not experience pain, however, there are many ways that we can try to relieve this. Every patient will be regularly reviewed to assess the cause of the pain and treat appropriately. To do this we may use medication, position change and complementary therapy.

Nausea and vomiting

If there are any signs of nausea or vomiting we can administer anti-sickness medication to relieve this.

Frequently asked questions

Some people find the answers to the following questions helpful.

How do I tell my children about my loved one's condition?

Be as honest as you can, be led by the questions your children ask.

Further support is available from nursing staff on the ward and the supportive care team.

Further information and literature can be accessed in the cancer information centre, located along the glass corridor.

Can I stay with my loved one when they are dying?

You can stay as long as you feel you need to with your loved ones during and after death. Support is also available throughout this very difficult time.

If my loved one deteriorated and I wasn't around what would happen?

Your loved one is regularly checked by the ward staff who are experienced in caring for patients at the end of their life. They would make every effort to contact you as soon as possible. Your loved one would continue to be comforted by the staff until you arrive.

Can my loved one hear me even if they are unconscious?

Even when patients are unable to communicate hearing may well be preserved. It is often comforting for your loved one to hear familiar voices or music.

Is it best to let my loved one rest and not disturb them?

Everyone is different. For some being surrounded by family and friends is important. For others a quiet and calm environment gives them peace. We will try and ensure a side room is available where possible.

What happens if my loved one gets better?

Occasionally your loved one's condition can improve. They will be reviewed daily so any changes in condition will be assessed and treatment plans changed accordingly.

Syringe driver

We will sometimes need to commence a syringe driver (a pump) that will enable patients to have their vital medications continuously over 24 hours. This means that patients will be more comfortable and reduces unnecessary disturbance.

Eating and drinking

In the last few days of life patients may not want to eat and drink. Whilst for many this is a gradual reduction in dietary intake for others it can be more sudden.

Food and drink can be important for comfort and psychological wellbeing. Patients will be supported to receive food, and drink for as long as possible.

In hospital, nursing staff would discuss any changes to treatments in nutrition and hydration with yourself and/or your loved one.

Many patients and their families are concerned about hunger and thirst at the end of life. Many wonder if the person should receive a fluid drip, or tube feeding.

The risks of artificial nutrition and hydration often outweigh any benefits but this would be assessed on an individual basis.

If your relative is receiving artificial fluid or nutrition there would be a detailed discussion should it need to be stopped.

Diabetes management

Appropriate management of diabetes is very important. The advice for patients will be dependent on various factors and is individual.

It may be that there is no need to take as many diabetes tablets or have as many insulin injections as previously, but these decisions will be discussed by a health care professional at the relevant time. There may also be a reduction in the frequency of blood glucose testing that is required.

There is advice available from the diabetes specialist nurse (DSN) at The Christie who supports the management of inpatients who have diabetes.

In the last few days of life, interventions and monitoring will be kept to a minimum to keep your loved one comfortable without compromising safety (e.g. avoiding low blood glucose levels).

Psychological support

The psycho-oncology team offers support to the patients and their loved ones who are nearing the end of their life. We can offer input when patients/loved ones are very distressed or anxious and give space for people to talk about their concerns and try to help address these. We work alongside the supportive care team offering specialist psychological support, medication advice and review.

Discharge planning

You may be referred to the complex discharge team if you and your family have identified that your preferred place of care/death is at home or hospice. Where home is the preferred place of care we will aim to achieve this as quickly as possible. Discharge to a local hospice is something we would also support you with. We can discuss the services that are available to support you at home following discharge which include your GP, district nurses, Community Macmillan and carer support.

Spiritual care

Patients in the last days of life and their loved ones may benefit from chaplaincy support, whether they are religious or not. The chaplaincy and spiritual care team are expert listeners and can spend quality time with you, giving you space to talk through all the feelings you are going through on a day-to-day basis. They are trained in the dynamics of grief and loss and will be able to guide you through the process of supporting your loved one in their last days of life, and of beginning to let go of them when they pass.

They can also help with funeral planning and can signpost you to agencies that may be of help in the days after your loved one's passing.

Many religions have prayers or rituals around the end of life which will bring a huge amount of strength and comfort. If your loved one belongs to a particular religion, our chaplaincy and spiritual care team can either provide these prayers for you at your loved one's bedside, or they can arrange for an appropriate faith representative to visit.

If the team haven't yet introduced themselves to you, and you would like to see them, please ask a member of staff.

Complementary therapy

The complementary therapy service offers a range of therapeutic interventions to support patients in the last days of life. Every treatment is adapted to each patient. We offer massage, therapeutic touch, aromatherapy, hypnotherapy, creative visualisation and stress management techniques.

The team also provides treatments to support carers either at the bedside, in the dayroom, or at our drop-in sessions (Tuesday and Thursday 4 - 6pm Rehabilitation Unit, Wednesday 1.30 - 3.30pm Relaxation Room, department 3). The service is free to both patients and their carers. Please ask a member of staff if you feel you could benefit.

Maggie's Manchester

The centre provides a full programme of practical and emotional support, including psychological support, benefits advice, nutrition workshops, relaxation and stress management. Contact Maggie's on **0161 641 4848** or email manchester@maggiescentres.org

Cancer information centre (department 3)

Staff at the information centre are experts in listening/ helping with a person's concerns and provide written information and signposting to other services in your local area.

These services include hospices for both day care and inpatient care, support services such as Beechwood Cancer Support, Neil Cliffe Centre and other cancer support groups/ centres that are local to the person's area.

A wide range of written information is also available to support patients to plan ahead and focus on some of the practical decisions they need to make, e.g. around advance decisions to refuse treatment, creating a lasting power of attorney and making a will. They can also signpost individuals to benefit advisers who can support with addressing any financial concerns that may arise.

They can also provide written information for both the patient and their carers about living with advanced cancer and end of life care and support.

Bereavement suite

If you would like to visit the bereavement suite to see the facilities and ask the staff any questions, the nurse caring for your loved one can organise this for you.

Religious representatives are also able to visit the department and talk about what they require from us with any spiritual/religious requirements.

If you wish to discuss tissue/organ donation, or anything in regards to the care after death, please contact the team on **0161 446 3898**.

There is also a bereavement booklet which has further details. Please ask staff to issue you this if you would like more information.

Communication record

This is included overleaf. It is somewhere you can write down information you want to share with those involved in providing care.

Information you provide will help staff understand what is important to the person they are caring for and for you and others who are close to them.

Please use this booklet to advise what we may need to consider when caring for your loved one and write down any questions/comments you may have. Please leave your contact details.

Please note:

This booklet will be accessed by professionals on a regular basis and supported with ongoing face-to-face communication.

Useful contact numbers

The Christie supportive care team – **0161 446 3072**

Chaplaincy – **0161 446 3097**

Complementary therapy – **0161 446 8236**

Nutrition and dietetics – **0161 446 3729**

Psycho-oncology – **0161 446 8103**

Bereavement suite – **0161 446 3898**

Cancer information centre (department 3) – **0161 446 8100**

Maggie's Manchester – **0161 641 4848** or email
manchester@maggiescentres.org

Other sources of support

Your local GP

Your local hospice

Your local Community Macmillan or District nursing team

Macmillan Cancer Support – **0808 808 00 00**

Beechwood Cancer Care Centre – **0161 476 0384**

Samaritans – **116 123** (Freephone)

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence.

If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

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www.christie.nhs.uk

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