



# Where to get help

**Knowing where and who to go to for  
your individual needs.**

When your own care needs or the needs of someone else changes, thinking about who can help and where to go for the right support and information are just some of the concerns you may have.

*because  
you matter*

**St Nicholas**  
Hospice Care

A Registered Charity No. 287773

# Some places to start

You might have questions to ask, but equally you might not know what to expect. These are some of the things you might want to begin to think about. You might find the suggestions below to be helpful as a prompt or even as a conversation starter. Some of these things will be relevant to you, others may not be.

## Managing Changes

- Before making decisions about additional equipment or aids, have your needs assessed by the relevant professional. The best organisation to contact is Suffolk Community Services (details on page 7).
- Adapting your home can take time and you may need help with funding. Again getting in touch with Suffolk Community Services could be a good first step.
- If you are being assessed for care needs, give lots of detail and always describe your worst day, not your best, this will help you get the appropriate level of support.
- If you have not previously accessed benefits, this can feel uncomfortable, but it is important to find out what you are entitled to. The Department for Work and Pensions offer advice.

## Challenging Emotions

- It is normal to have changing feelings and emotions. Even though these feelings are intense, they can be difficult to describe. They are not always easy to understand or cope with and can affect different people in different ways. They can affect the way that you make decisions, take in, and accept information.

## Difficult Conversations

- Planning for the later stages of your illness will feel daunting. It probably isn't something you want to think about. Even the thought of starting these conversations might leave you feeling intimidated.
- However, having these conversations early will let the people around you know your wishes. With your thoughts ordered you might feel calmer and comforted.

## Other Areas to Consider

- Support from other people affected by illness can help to reduce feelings of isolation and loneliness.
- There are some details in this leaflet about groups and organisations that may help, or you can speak to someone at the Hospice.



# Finding the **Right Help** with **People and Services**

Use this space to note down important numbers and people to get in touch with. Even if you don't need them right now, it's helpful to have them all in one place. These may be:

- those close to you
- people who have been through similar experiences
- voluntary or local organisations
- your GP or nurse
- a doctor you see at hospital
- your district nurse
- anyone else that might be helpful
- someone from the Hospice

**Name of Person or Service:**

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**Contact details:**

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# What next

While it is hard for most of us to ask for help, it is important that you don't lose your independence or sense of self. Asking other people makes them feel involved and may help you remain as independent as possible. That can help you to further build your resilience and be more in control.

If you are not sure where to start this is our website and our helpline, together with other nationally recognised organisations that can offer advice.



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

**01284 766133**

## **Suffolk Community Services:**

[www.suffolkcommunityhealthcare.co.uk](http://www.suffolkcommunityhealthcare.co.uk) or  
0300 123 2425

Their priority is to deliver high quality, safe and efficient healthcare to the people of Suffolk, aiming to bring patients personalised, joined-up care within available resources.

## **Suffolk County Council:**

[www.suffolk.gov.uk](http://www.suffolk.gov.uk) or 0345 606 6067

Local government services and information. Simple, clear and fast. Includes further detail about social services. See also Suffolk Info Link: [infolink.suffolk.gov.uk](http://infolink.suffolk.gov.uk).

### **Suffolk Family Carers:**

[www.suffolkfamilycarers.org](http://www.suffolkfamilycarers.org) or 01473 835477

Helping family carers of all ages across Suffolk to get the support they need to live fuller lives.

### **Citizens Advice:**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) or 03444 111 444

Provide free, independent, confidential and impartial advice to everyone on their rights and responsibilities.

### **Macmillan Cancer Support:**

[www.macmillan.org.uk](http://www.macmillan.org.uk) or 0808 808 00 00

A cancer diagnosis can affect everything. Macmillan Cancer Support can help you find your best way through.

### **Marie Curie:**

[www.mariecurie.org.uk](http://www.mariecurie.org.uk) or 0800 090 2309

Provide care and support for people living with any terminal illness, and their families.

**Age UK:** [www.ageuk.org.uk](http://www.ageuk.org.uk) or 01473 351 234

Age UK's vision is to make the UK a great place to grow older. They aim to do this by inspiring, supporting and enabling people in a number of ways.

### **The Cinnamon Trust:**

[www.cinnamon.org.uk](http://www.cinnamon.org.uk) or 01736 757 900

The National Charity for the elderly, the terminally ill and their pets.

### **Department for Work and Pensions:**

[www.gov.uk/government/organisations/department-for-work-pensions](http://www.gov.uk/government/organisations/department-for-work-pensions) or 0800 731 7898

The Department for Work and Pensions (DWP) is responsible for welfare, pensions and child maintenance policy.

# Helpful thoughts

## 1. Don't lose sight of yourself

With so many changes, it can be easy to lose sight of what makes you feel like yourself and what you enjoy doing. It may just be doing something special with your family and friends or something you have always wanted to do, but haven't had the chance.

## 2. Your journey

The decisions you make about your care are yours. Speaking with your family or those supporting you may help them understand your decisions. Do what's right for you.

## 3. It's never too early

Talk to people about your wishes as soon as you feel comfortable. Many people report that having their wishes known made them feel calmer and more in control.

## 4. Making notes

Keep a notebook of non urgent questions as they come to you. That way, when you meet with someone, you'll have it all to hand.

## 5. Medical needs

When talking about your condition, make sure to describe your worst days as well as your best in order to better inform the people involved in your care.

## 6. Finances

Accessing benefits for the first time can be worrying. However, it's important to find out what you are entitled to.

## 7. Equipment

Think about what you might need in the future, as sometimes it takes time to get the equipment you need.

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As well as the detail in this leaflet, you may also find our Memorable Moments and Gathering Support information useful. If you would like to find out more please get in touch.

or alternatively you can find more in our website [www.stnicholashospice.org.uk](http://www.stnicholashospice.org.uk)