

# WHAT MATTERS?

AN E-NEWSLETTER FOR THOSE APPROACHING OR PLANNING FOR END OF LIFE IN CORNWALL



Vol 3 - Summer/Autumn

## SPECIAL POINTS OF INTEREST:

Recording your wishes:  
*Advice about Wills, Funeral planning and Organ Donation* 6-7

'Preferred place of care' ..., *have you thought about it?* 6-15

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# Did you know that Cornwall Hospice Care has a Useful Links Directory with links and contact information for a range of organisations and charities.

  
**Cornwall Hospice Care**  
 • Mount Edgumbe Hospice • St Julia's Hospice •  
 Caring for our community

## Useful Links Directory

[www.cornwallhospicecare.co.uk/our-community-services/](http://www.cornwallhospicecare.co.uk/our-community-services/)



**Scan Me!**



•Mount Edgumbe Hospice •St Julia's Hospice •

*Caring for our community*

# Community Services

**We are here to help you find the right support for you.**



**Neighbourhood Hubs:** Supporting people living with a palliative/terminal illness or a deteriorating progressive disease and their loved ones



**Virtual Community Friendship Café:** Join our social media page on Facebook if you are struggling with social isolation, loss, long term illness or a palliative condition



**Listening Ear Service:** Telephone calls for those who are recently bereaved and are in need of some support, information and signposting



**Useful Links Directory:** For a range of topics including cancer, mental health, planning for end of life, bereavement and general health



**Bereavement Support Groups:** Each group provides a space for those who are bereaved and seeking social connections with others who are also experiencing grief



**All of our services are FREE for everyone to access. Call 01726 829874 for more information, visit our website or scan our QR code.**

**[www.cornwallhospicecare.co.uk/our-community-services/](http://www.cornwallhospicecare.co.uk/our-community-services/)**

# Advance Care Planning

**NHS**  
Royal Cornwall Hospitals  
NHS Trust

Helping you plan ahead for a time of failing health. Because we all deserve the opportunity to communicate what matters to us.



We want to support you to think about your wishes and preferences for the future. Writing down your preferences in an **Advance Care Plan** can help those around you to understand what matters to you.

## What is Advance Care Planning?

Advance care planning encourages you to discuss and write down how you would like to be cared for and what you would like to happen if you are unable to communicate your wishes.

Having these discussions, or completing an advance care plan, is entirely voluntary. The only legally binding decision some people wish to make is an Advanced Decision to Refuse Treatment. This can be part of, or separate to, your Advance Care Plan.

And because your health, and your preferences, can change over time, any decisions that you make can be changed by you at any time in the future.

If you'd like a template for an advance care plan, or to discuss how to write one, please speak to the team looking after you at the hospital.

For more information on completing your Advanced Care plan visit the web link below or scan the QR code

[www.royalcornwall.nhs.uk/services/advance-care-planning/](http://www.royalcornwall.nhs.uk/services/advance-care-planning/)

**You can scan me here!**



## Neighbourhood Hubs—Cornwall Hospice Care

**FREE** support, practical advice, information and treatment for people living with a palliative/terminal illness or a deteriorating progressive disease including their carers. Currently delivered by experienced occupational therapists and physiotherapists, over the telephone.

This service is centred around your needs and what matters to you.

Referrals can be made via the link below or by calling

**01726 829874**



*We can help you take  
back control and  
live as well as possible*

*"I received all the help and guidance I could have possibly needed, this help was so easy to access, I couldn't believe it"*

*"Great service, the advice I was given was very helpful and ideas to help me along the way were great "*

*"Thank you all so much...I know I have support at the end of the phone"*

*"You shone a light on a very overwhelming situation—Thank you"*

[www.cornwallhospicecare.co.uk/our-care/neighbourhood-hub/neighbourhood-hubs-referrals/](http://www.cornwallhospicecare.co.uk/our-care/neighbourhood-hub/neighbourhood-hubs-referrals/)



**PASS IT ON**—PASS IT ON BEFORE YOU PASS AWAY ASKS YOU TO CONSIDER WHAT YOU WANT IN DEATH AND TO START IMPORTANT CONVERSATIONS.

Dying Matters. It's important to talk about death while still very much alive. Do your family know if you're an organ donor for instance, or what you want to happen at your funeral? Our 'Pass it on before you pass away' campaign asks you to consider what you want in death and to start important conversations. It encourages you to consider opting in for organ donation and to complete an Advance Decision, which explains what you would want if you couldn't speak for yourself. There's a free leaflet available to help you start the conversation.

To find out more visit:

**You can Scan me too!**



[www.cornwallhospicecare.co.uk/our-care/pass-it-on/](http://www.cornwallhospicecare.co.uk/our-care/pass-it-on/)

# Worried about recording your wishes?

## Navigating Wills, Organ Donation and funeral plans...

All of the above forms part of your Advance Care Planning and involves making decisions, ahead of time, about how someone wants their health needs managed. It also involves letting family members and health care providers know those preferences.

### Who needs to think about these things?

Pretty much everyone. All of us could one day have an accident or a medical crisis that leaves us unable to make or communicate our own health care choices. By planning and communicating ahead of time, families and health care teams are aware of our precise wishes, should the time come. It is not just for people who are living with a terminal illness.

### Writing a Will

A Will is a legal document that gives instructions about who should receive a person's money, belongings and property after they have died.

When a person dies, their money, belongings and property is called their estate.

A Will can also give instructions about who would look after underaged children (legal guardian), funeral instructions and who would sort out the estate (executor).

There are special rules if a person dies without a Will. This means it take much longer for the estate to be dealt with and money, belongings and property may not go to whom the person would have chosen.

A Will is a legal document. A person can write a Will themselves if they follow the appropriate rules. They can also employ a Will writer or a solicitor.

### For more information on writing a will visit:

Making a will: Overview - GOV.UK  
([www.gov.uk](http://www.gov.uk))

<https://www.gov.uk/make-will>



Scan me

Making a will - all you need to know - Age UK

<https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/making-a-will/>



Scan me

## Funeral Planning

A person may wish to plan their funeral because they have specific wishes, they want to make it as easy as possible for their loved ones. It may or may not include a pre-paid plan set up with a funeral director. A funeral plan means the person is more likely to have a funeral that reflects their wishes and it can take a lot of worry and stress away from their grieving family.

The key elements are about the person's choice of burial or cremation and religious or non-religious service and where they would like to be buried or their ashes kept. But the person may also want to plan the type of coffin, specific readings, songs and music, flowers, who would benefit from donations, dress code, food etc. Nowadays people can really personalise their own funeral which grieving families and friends often find comforting.

### For more information on funeral planning visit:

Search 'funeral' at  
<https://www.ageuk.org.uk>  
<https://www.mariecurie.org.uk>



Or Scan the direct links on the top right.



## Decisions about Organ/Tissue Donation

On 20th May 2020 the law around organ donation in England was changed to an opt out system. It is now considered that every individual agrees to become an organ donor when they die if they are 18 or over, have not opted out and are not in an excluded group. However there still is a choice and people can register or amend their decision at any time.

### For more information on organ and tissue donation visit:

Organ donation law in England - NHS Organ Donation



*Many thanks to Gwendoline Treseder, Occupational Therapist at Cornwall Hospice Care for providing this information. Part of her role is within the Neighbourhood Hubs who offer support, practical advice, information and treatment to people living with a palliative/terminal illness or a deteriorating progressive disease.*

**Find out more about how  
our team can help you here**

[www.cornwallhospicecare.co.uk/our-community-services/](http://www.cornwallhospicecare.co.uk/our-community-services/)



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Caring for our community

# End of life care



The NHS has a page on its website dedicated to this. Here you may find the answers you may have to questions you have. This guide is for people who are approaching the end of their life. Some parts of it may also be useful for people who are caring for someone who is dying, or people who want to plan for their own end of life care.

It covers what to expect, thinking about your wishes for your future care, and looking after your emotional and psychological wellbeing.

## What you can expect from end of life care

This section contains information about what end of life care involves, when it starts, and things you may want to think about.

These include advice on how to cope financially, and how and where you can be cared for, for example:

A care at home, care in a care home, care in hospital, hospice care or care in a care home

## Planning ahead for the end of life

This is sometimes called advance care planning, and involves thinking and talking about your wishes for how you're cared for in the final months of your life. This can include treatments you do not want to have.

Planning ahead like this can help you let people know your wishes and feelings while you're still able to. Letting your family know about your wishes could help them if they have to make decisions about your care.

## Your wellbeing

Looking after your health and wellbeing is important when you're living with a terminal (life-limiting) condition.

These pages aim to answer questions you may have about pain and other symptoms, and provide ideas for coping.

**For more information visit:**

**[www.nhs.uk/conditions/end-of-life-care/](http://www.nhs.uk/conditions/end-of-life-care/)**

**Scan me for a direct  
weblink**







## After you're gone, we promise to be there for your cat

We know your cat means the world to you, which is why Cats Protection promises to be there for them after you're gone.

By registering with our free Cat Guardians service you can be assured that, after you pass away, our caring employees and volunteers will look after your cat until we find them a loving new home.

Find out more about how Cat Guardians could bring you real peace of mind – request your FREE leaflet today.

Call **01825 741 291** (Mon – Fri, 9am – 5pm)

Or go online [www.cats.org.uk/catguardians](http://www.cats.org.uk/catguardians)

**We promise to never put a healthy cat to sleep**



**Cats Protection's free Cat Guardians service helps make sure there's always a cuddle-giver, behind-the-ear-scratcher and food provider for your feline friend – even if you pass away.**

For more information visit:

[www.cats.org.uk/what-we-do/catguardians](http://www.cats.org.uk/what-we-do/catguardians)





## Gold Standards Framework Care Home Programme for care home professionals

We are delighted that Cornwall Hospice Care are now an accredited provider of the Gold Standards Framework (GSF) Care Home Programme. As a Regional Training Centre the hospice can provide training workshops for those care homes wishing to undertake the training.

The programme is a tried and tested evidence-based, quality improvement approach, used by thousands of teams, affecting the care of people in their last year of life in all care settings.

Key aims of the programme are to:

- Improve the quality of care
- Improve coordination and collaboration
- Improve outcomes for people, enabling more to live and die where they choose, reducing avoidable hospitalisation

The GSF Care Homes Training Programme has a long and very successful history in supporting and enabling the staff in care homes to provide top quality care for all people nearing the end of their life, including the final years, months, weeks and days of life, helping to ensure that the final years are 'the golden years'.

You can find out more about the Gold Standards Framework for Care Homes Training Programme by visiting;



[www.goldstandardsframework.org.uk/care-homes-training-programme](http://www.goldstandardsframework.org.uk/care-homes-training-programme)

**If your care home would like more information or would like to undertake the programme please email Jo Smith, Education and Training Lead, Cornwall Hospice Care at [jsmith@cornwallhospice.co.uk](mailto:jsmith@cornwallhospice.co.uk)**



## Our Cornwall Hospice Care Podcast: Two Old Choughs

Join our Two Old Choughs, Gina Starnes, our Clinical Director and Tamsin Thomas, our Head of PR and Communications, as they talk all things Cornwall Hospice Care.

This podcast began in January 2020 as we celebrated the anniversary of 40 years of hospice care in Cornwall, a story that started with the opening of our Mount Edgumbe Hospice.

Each episode features special guests from around our charity, from our hospices, shops, fundraising teams, supporters and many more as we talk about subjects close to hospice care and end of life.

We look at difficult conversations in our 'Be Brave and Plan Ahead!' podcast and talk about bereavement in an episode entitled 'Permission to Grieve'. On a lighter note, our former Medical Director Dr Debbie Stevens reflects on a career in palliative care in Cornwall and Cornish gardener George Kestell talks about the peace gardening brings and his personal story of the care we provide.

**Available on Spotify, Apple Podcasts, Google Podcasts, and many more popular platforms.**

**[www.cornwallhospicecare.co.uk/our-new-podcast](http://www.cornwallhospicecare.co.uk/our-new-podcast)**

**You can also follow Cornwall Hospice Care on Facebook, Instagram, Twitter and LinkedIn for updates from across our charity!**

## END OF LIFE CARE

NHS Kernow views end of life care as a high priority and we want to ensure high quality end of life care. We want to enable choice for local people so that they can choose where they want to receive care and to ensure that they receive the best possible support.

## SUPPORT IN CORNWALL

### Community specialist palliative care nursing team

Each GP surgery has an allocated palliative care nurse. Their aim is to ensure all patients with complex palliative care needs receive high quality symptom control assessments, psychological support and advice to meet their individual needs. Nurses work closely with a range of health professionals in the community, hospital, hospices and other voluntary and statutory agencies.

If you think you would benefit from this service please discuss with your GP or hospital team who can refer you.

### Out of hours palliative GP service

Kernow Health CIC provides an out of hours palliative GP service. **Telephone 01872 224050.**

### Cornwall hospice care

A palliative care advice line is available to healthcare professionals 24 hours a day, 7 days a week. This provides access to specialist nursing and medical advice at any time on symptom control, syringe driver and drug use, appropriate place of care and management of palliative care emergencies. **Telephone 01736 757707.**

They also operate a palliative care email hotline, which is available to healthcare professionals requiring advice quickly but without the urgency of a direct telephone conversation. Email requests for advice will be responded to within 24 hours by the consultant on call that day. Email the palliative care email hotline at [cornwall.spcadvice@nhs.net](mailto:cornwall.spcadvice@nhs.net)

### Marie Curie

Call the **Marie Curie support line on 0800 090 2309.** Open Monday to Friday, 8am to 6pm, and Saturday, 11am to 5pm. You can also get terminal illness support on their website.



To find out more visit:

[www.kernowccg.nhs.uk/your-health/end-of-life-care/](http://www.kernowccg.nhs.uk/your-health/end-of-life-care/)

Or Scan the QR code





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## Listening Ear Service

**Are you recently bereaved and in need of some support?**

This service is for anyone who is isolated and vulnerable in our communities who have experienced the recent death of a loved one.

Although not a counselling service, we offer **FREE** information, support and signposting via the telephone for **6 calls of up to an hour.**

To make a referral please call **01726 829874**  
or email

**[communityservices@cornwallhospice.co.uk](mailto:communityservices@cornwallhospice.co.uk)**



**[www.cornwallhospicecare.co.uk/our-community-services/](http://www.cornwallhospicecare.co.uk/our-community-services/)**

WHAT MATTERS?

A NEWSLETTER FOR THOSE APPROACHING OR PLANNING FOR END OF LIFE IN CORNWALL



## Free services for unpaid carers



New  
courses  
added for  
2022

Putting carers first

“It's life changing  
... being with  
people who  
have the same  
struggles and  
know what you're  
going through.”

## An overview

Whether you're paying bills, giving medicine, doing laundry, giving emotional support, keeping appointments, washing bodies, all on a regular basis or looking after a loved one in their home, then you're a carer.

*Look at it this way if you didn't do what you do for that person could they manage on their own?*

We know that being a carer can be isolating. Being a carer can also take up all your time. It can also be difficult to find out what support is out there for you. We are here to support you in managing your caring role.

**We deliver a wide range of free services, designed with the help of carers.**


We will find a service to suit your needs. All of our services will help carers to manage their caring role but more importantly ensure they look after themselves. Written and designed with the help of carers.

Caring for a family member or friend requires specialised skills. Caring is often unexpected and comes with no training on how to cope.



Find us on Facebook!

**Contact us for more details  
and see how we help:**

 @PromasCIC

(e) [info@promas.co.uk](mailto:info@promas.co.uk)

(t) 01736 339226

(m) 07775 756454

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

# Where would your preferred place of care be as you reach the end of your life?

***Gwendoline Treseder—Occupational Therapist  
Cornwall Hospice Care***

This is not an easy thing to think about but it is worthwhile. As people become more poorly through illness, sometimes they lose the ability to make or communicate decisions and preferences. So it is worth considering, ahead of time, what you might like your end-of-life to look like and where you might like to be. Is it important for you to be at home or do you feel this would be too much of a burden on your loved ones? Would you prefer a nursing home, hospital or hospice? Do you have a definite wish of where you do not want to be? It is important that you talk about your wishes with your loved ones so that they are aware.

Writing them down would also be very useful to help the professionals working with you to make the right document. You may wish to use a document such as a statement of wishes and preferences.

You can find more information here:



<https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-statements/>

and a form to complete if you wish here:



[http://gsfcentre.co.uk/cd-content/uploads/files/ACP/Thinking%20Ahead%20\(3\).pdf](http://gsfcentre.co.uk/cd-content/uploads/files/ACP/Thinking%20Ahead%20(3).pdf)

**You can  
scan me  
too!**



## Cornwall Hospice Care Stories

### Clare Bray - Community Engagement Officer talks to our Bereavement our Family Support Service

Marie Brooks and Ange Bunt together form Cornwall Hospice Care's Patient and Family Support Services, Marie is based at St Julia's Hospice in Hayle and Ange Covers Mount Edgcombe Hospice in St Austell. They offer counselling and support to patients and their families whilst in the hospice, at end of life and continue that support for families after a bereavement, working alongside other professional colleagues in the community.

Their roles enable them to spend time with patients and their families, to facilitate important conversations. "When a patient is admitted to one of the hospices the team try and meet with each member of the family and the patient themselves. Quite often the patients focus is on the relative. Wanting to make sure that the relatives are well cared for, that they will have all they need and will get support. Relatives, on the other hand are focusing on the patient. It's our job to meet with them to gain an idea of their need, it takes time to build that relationship so that they can open up and begin to trust you enough to talk about how they are feeling. That can take place over many days, many meetings with them."



*Marie Brooks—Counsellor St Julia's Hospice*

"We are there to support the patient to maintain their health, independence, and autonomy. We encourage patients to enjoy time out of the hospices, visits home or enjoying trips out in the car with family members. It is important to set achievable goals whilst still making memories."

"The word hospice can mean different things to different people. For some just that word will make them fearful as there are a lot of preconceived ideas about what coming into the hospice means. However, that worry is soon dispersed. They meet the staff, see the lovely rooms. Once they have settled in, they then see it is vastly different to what they expected. For patients who come back for multiple admissions, they look forward to coming back, the fear has gone. When we talk to patients the word they use most regarding how they feel is 'safe' and relatives will often say the same."

When it comes to having those big important end of life conversations with someone, the team both said the same thing, "It's important to treat each person as an individual when it comes to talking with them, some people are just never ready to have those kinds of conversations. It is about facilitating the conversations for as far as they want to go with them."

"If a patient is coming to the end of their life, we can be a support for the family both emotionally and practically, going through with them what will need to be done and how they can prepare. Some patients have had very open conversations about what they would like at end of life, the funeral may be planned, everyone knows their wishes, and this can take a lot of weight off their family's shoulders. We try and encourage families to do this together, to help alleviate the extra pressure, including addressing financial issues."

During a patients stay in the hospice, Marie and Ange are on hand for family members to ensure they remain updated, medical staff are on hand in person or on the phone to answer any questions they may have. They are there to be alongside families when bad news is



broken and will be there for as long as is needed. If a patient is to be discharged, they will be there to help with planning, and to give information on what help is available and where to find it.

Ange and Marie agreed that if they had learnt anything from working in their roles it would be to write down and discuss what their wishes are. "I have had some people come back for counselling after bereavement who feel massive guilt because they didn't know what their loved one wanted."

Marie recounted a recent experience, "I recently spent a great deal of time with a patient as there was no next of kin. We talked and I documented all our conversations and was able to pass on the information to the solicitor. Although they had done a will with her, they had no idea where she wanted to be buried, but she had told me she wanted to be with her Mum and Dad and where they were."

Ange said she had experienced something similar, "I'll never forget it, he was a fairly young chap, he was dying. I went to his room and his wife was there sobbing, she didn't know what his wishes were. She had tried to talk to him about it, but he had never been ready, but I had talked with him and had written everything down. I think some people think it is tempting fate to talk about it, he hadn't wanted to know, hadn't wanted to talk about it. One day he realised he was close to the end, we went to the patient lounge, we documented everything; what coffin he wanted, who he wanted to write the eulogy, who he wanted to speak, what he wanted afterwards. He could remember two songs that he wanted but couldn't remember the last one. I suggested it might be nice for his wife to choose a song which he thought was a good idea. When she looked at it all, she said to me I know which one it is."

Marie and Ange have also arranged for people to write wills, letters to friends and family and chaplaincy visits. Creating keepsakes such as memory boxes, handprints

on canvas, creating memory books with children and once casting someone's hand in Plaster of Paris. Giving children teddy bears from their loved one has also proved to be a great comfort. Perfume or aftershave can be put on the bears to add that extra feeling of closeness. "If there is anything that they want help organising, we try and do it. Our job is also to help children to understand and to prepare for what is happening, when we first meet a family, we try and do a family tree so that we make sure we reach as many family members as possible."



*Ange Bunt—Counsellor Mount Edgecumbe Hospice*

"Photographs are also helpful to build an image of the person before the illness, what they were like and what was important to them. Each patient is more than the illness itself; they are very much still part of that family. It is important to understand how this change has affected those around them."

Ange and Marie's involvement with families continues after a patient has died as they offer counselling to families. Relatives can find it very comforting to talk to the same person again. "Working here, I always feel privileged that I know the person they are talking about, relatives are comforted when you say you can remember a loved one."



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



## Celebrate Life • Manage Death

Aura guides people through life's difficult events, connecting them with the knowledge, tools and support to approach death properly and live a fuller life.

# Why Aura?

It's difficult to talk about issues related to end of life and even harder to prepare. Aura provides a helping hand with:

**Aura End of Life Planning** - record, store and share useful information, end of life preferences and celebrations

**Aura Life Commemoration** - build a collaborative multimedia memorial or life story with the people and experiences that matter most

**Aura Content & Communities** - guides, resources and conversations with real people and death professionals

### Our Mission



To become a movement for change in the way we approach death.



Give people the space to embrace their lives, and improve the way we think, speak and feel about dying.



To discuss and celebrate life and death, and ensure that both are managed properly.

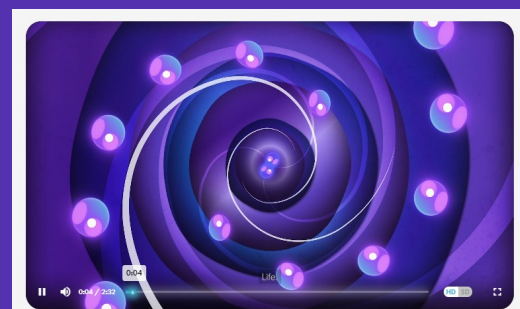
To find out more visit [www.aura.life](http://www.aura.life)

Or watch their YouTube video follow the link here

<https://youtu.be/gKwudUpMuiA>

or

Use the  
hyperlink





**Cornwall Hospice Care**  
**Porthpean Road**  
**St Austell**

**Telephone:**

01726 65711

**Email:**

[communications@cornwallhospice.co.uk](mailto:communications@cornwallhospice.co.uk)

Cornwall Hospice Care has two hospices; St Julia's Hospice in Hayle and Mount Edgumbe Hospice in St Austell.

You can support our Cornish charity by shopping in our stores from Bude to Penzance, taking part in one of our fundraising events from Cream Teas to Marathons or by giving your gift of time to volunteer.

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

## Legacies

You can help those people with terminal illness and their families when they need it most, by leaving Cornwall Hospice Care a gift in your Will.

You help fund our vital work. Your gift, large or small, can make a big difference as it will ensure we can care for adults in Cornwall.

If you would like to find out more about leaving a gift to Cornwall Hospice Care in your Will, please contact Paul Jones on

**01726 66868 and choose option 2** or email [pjones@cornwallhospice.co.uk](mailto:pjones@cornwallhospice.co.uk)

**Thank you**



Tracey Davey—Coordinator



Helen Treleaven—Manager



Clare Bray—Engagement Officer

**Cornwall Hospice Care Community Services Team**



Lollie Brewer—Engagement Nurse