

WHAT MATTERS?

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



• Mount Edgcumbe Hospice • St Julia's Hospice •
Caring for our community



Vol 2 – Winter/Spring 2022

SPECIAL POINTS OF INTEREST:

'Preferred place of care' - Have you thought about it? 3

Other choices— What are End of Life Doulas? 8-9

INSIDE THIS ISSUE:

Community Connect Update 2

Pass It On Before You Pass Away 2

Neighbourhood Hubs 4

Other ways to cope with Chronic pain 4

Making plans for our digital lives 5

Canine Care Card and The Dogs Trust 6

Our Podcast 'Two Old Choughs' 7

Community Palliative Care and how they can help 10

Our Listening Ear Service 11

Cornwall Hospice Care Stories—Why we fundraise. 12-13

Useful Links Directory 14

Falmouth Carers Survey 15

Community Services offerings 16

The Cove Cancer Support Centre 17

Hospice Legacies and contact info 18



Community Connect update

It's been a busy time of year for Community Connect and we continue to work with people experiencing bereavement or loss across the Coastal Cluster of GPs and Truro GP surgeries through our social prescribing and community-based activities. We will shortly be launching our new mental health and wellbeing coaching sessions for young people aged 16-30 and this can be for anyone experiencing loss, alongside this we work closely with Shallal to offer sketchbooks on prescription to

support people who maybe experiencing loss or grief. Our health coach Danny can offer one to one session for anyone that may feel ready to do some more movement or exercise especially if someone has experienced loss and may not feel ready to go back into groups or regular activity. Please contact **health@imagineif.net** for further details.

Nikki Kelly

Community Connect



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 here



www.cornwallhospicecare.co.uk/our-care/pass-it-on/

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 decisions/choices. You may wish to use a document such as a statement of wishes and preferences.

You can find more information here:



www.compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-statements/

and a form to complete if you wish here:



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

**You can
Scan me
too!**



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/

Struggling to cope with chronic pain?

Chronic pain in Cornwall



Find out how the 10 Steps Pain Management Programme may be just what you are looking for.

Living with pain every day and night is often depressing, tiring, demoralising and leaves one feeling hopeless. We, the Chronic Pain in Cornwall taskforce, are working to increase awareness and helping to enable people with pain to understand how to “live well with pain” using “skills not pills” (or “skills as well as pills” but that’s not as catchy!)

Learn how to cope with things like physical inactivity, understanding what pain is and what it isn’t, acceptance, goal setting, sleep and mood.

**To find out more visit: www.my.livewellwithpain.co.uk
Or search “my live well with pain”**

Making plans for our digital lives



James Norris is the founder of the [Digital Legacy Association](#) and [MyWishes](#). The Digital Legacy Association is the global association dedicated to improving awareness and standards in areas relating to digital asset planning and digital legacy safeguarding. [MyWishes](#) is 'tech for good' planning software. It empowers the general public to document and share their wishes.



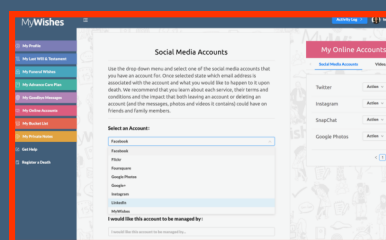
MyWishes

We are spending more and more time online. Just like we should make plans for the possessions we own in the real world, it is important that we think about and make plans for the possessions we have created and purchased online in the digital world.

You might have photos and videos uploaded to Facebook, Twitter or Instagram. You might own shopping points, have money in a PayPal account and an 'online only' bank account. Each account might be password protected. The computer or mobile phone you use to access them might also be password protected.

How can I make plans?

- **Think** about the accounts you have and the possessions (sometimes called digital assets) that they contain. Think about who you will share your details with one or more person you trust.
- **Curate** your favourite photos that have you captured within them! Your favourite photos might later be used to remember you and in doing so, form part of your digital legacy.
- **Document** your wishes. You might write a list of your online accounts and what you would like to happen to each of them.
- **Share** your wishes with your loved ones. Talk to them about your wishes and provide them with the relevant documentation.



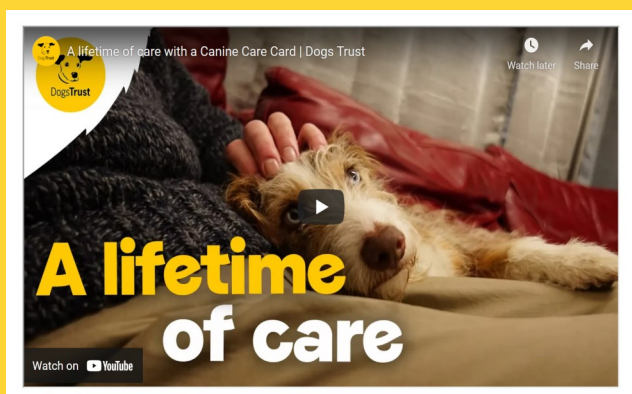
Templates, forms and support

There are a number of tutorials within the Digital Legacy Association's [For the Public](#) section. These guides help the general public better understand which platforms they use and how to make plans for each. A 'Social Media Will' template can also be downloaded (as an Excel document) from the platform. Once downloaded it can be completed and shared with someone you trust.

[MyWishes](#) free to use service includes a [Social Media Will](#) feature (shown in image above). Once completed it can be downloaded (PDF document), signed and shared with someone you trust. It can be edited and updated whenever circumstances change or you create an account for a new service.

A lifetime of care with a Canine Care Card

We know that the bond between you and your four-legged best friend is entirely unique. It's hard to imagine that anyone could love and care for your dog as much as you do. But we promise we will.



If you become seriously ill or pass away, Dogs Trust will look after your canine companion, help them get back on their paws, and find them a home.

Ensure your pet is cared for in the future

Follow these simple steps to become a Canine Care Card holder:



Choose your Dog Guardian - they can sign your dog over to us if you're not able to. Make sure it's someone you trust, like a friend, family member or solicitor. Ask them before you apply, as we'll need their contact details.



Complete the online application form - have the contact details of your chosen dog guardian and your dog's microchip number handy before you begin.



Receive your Canine Care Card - when it arrives fill in the details and pop it in your wallet or purse with your other cards, so that it can always be found.



Leave instructions in your Will - confirm your wishes in your Will to help ensure they're fulfilled. We suggest the wording: "It is also my wish that Dogs Trust cares for and/or rehomes my dog at the time of my death".

We love all dogs. And though we want to be able to care for any dog whose owner has passed away or become seriously ill, there are some cases where this might not be possible. Please take a minute to [make sure your canine friend is eligible for the service](#).

Register for your Canine Care Card here

www.dogstrust.org.uk/help-advice/canine-care-card



Our Cornwall Hospice Care Podcast

Two Old Choughs : A Tale of Two Hospices

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 Edgcombe 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

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

Other choices towards the end of life

Rosie Hadden tells us what its like to be an End of Life Doula

As an End of life Doula in Cornwall I feel one of my roles is to act as a connector for people around death and dying. I host monthly Death Cafés where the space is held open for people of all ages to come and share their experiences, their hopes and fears around death. Some people are coming with grief, others with a desire to think ahead and put in place some planning around their end of life care. They are also about creating communities of support, about creating spaces for connection, a space for people to share their stories and make new friends.

I work, too, walking alongside individuals who are nearing their end of life. Recently I supported a man and his family to help keep him at home during his dying and after his death, working in partnership with his paid carers. After he died, we wrapped him in white sheets and herbs, lit candles and surrounded him with flowers. We sang and chanted to him as we all wished him well on his journey. Together we created a beautiful space that enabled



his family to spend a few extra precious days with him until they felt ready to let his body go into the care of a sympathetic funeral director. The family wanted to be involved in every part of his care after he died. Together we washed his body in a ceremonial way and later we carried him out of his house and placed him in his sustainable woven coffin outdoors. Later it felt just right when the family asked me to hold space for his funeral service.

It is always an honour to walk alongside a client and their loved ones at the end of life. I feel each client teaches me so much and gives me resources that I can use with my next client. It makes me feel really

alive to work intimately in this very person-centred way with another person. We work together creatively to ensure that their life is lived fully right up until the moment of death and beyond. In sharing in the circle of grief as we create new rituals and ceremony together, I hope I can help to open up a tender time when those closest to the client can have a safe space and time to do what they need to do to honour their loved ones before and after death. It is not always easy and sometimes things can get a bit messy and confused. In working within the circle of support around a client I find that as long as I turn up with an open heart and a willingness to just be with what is in each moment of this work, somehow, we all find a way through, find a way into our shared humanity. I feel eternally thankful to the families who allow and trust me to step into this most intimate part of their living and dying. I hope that in some small way by allowing them their voice and choices they can also journey with some sense of ease through their inevitable grief and loss. It gives me a sense of fulfilment to be able to offer this work to Cornwall. It makes me wish that there were more of us Doulas, I dream of a day when everyone could have the opportunity to be accompanied in this way as they journey through death.

Aly Dickinson Director of End of Life Doula UK says;

End of Life Doula UK is a community of practice and a membership organisation. All our Doulas who are supporting a person (and those close to them) with a life limiting illness are insured, DBS checked and mentored. We are there to provide practical, emotional and spiritual support. You can find out more about what we do here www.eol-doula.uk/ and if you would like to connect please email us at operations@eol-doula.uk. Like us on Facebook www.facebook.com/EndofLifeDoulaUK and follow us on Twitter @livingwelldying.



END OF LIFE DOULA UK

Doing Death Differently

Community Specialist Palliative Care Nursing

The specialist palliative care nursing team are a resource for patients, their families and health care professionals in all community care settings.

The service offers expert support for patients facing a life threatening condition, irrespective of diagnosis, and in particular for:

- Complex symptom management
- Complex emotional/psychological issues
- Complex social/family issues
- Planning end of life care

The aim of the service is to ensure that patients with complex palliative care needs receive high quality assessment and advice to meet those needs through direct patient assessment and working with co-providers.

Referral guidelines

Referrals to the Community Specialist Palliative Care Nurse are appropriate when:

- The patient has symptoms which are complex or rapidly changing.
- The patient/carer has difficulty adjusting to diagnosis or advancing disease.
- Additional support is required when decisions about palliative treatment options are being made.

Referral process

- The referral is made by a Health Care Professional, with the patient's knowledge and consent.
- The Community Specialist Palliative Care Nurse works alongside GPs and hospital colleagues, who continue to have overall responsibility for their patients.
- Referral to the service will normally result in telephone triage within two working days.

Electronic referrals to be submitted to:

cpn-tr.spcreferral@nhs.net

If you wish to speak with a Community Specialist Palliative Care nurse please phone **01208 251300** between 9.00am and 4.30pm and your call will be returned. This contact number is available to patients 7 days a week (including Public Holidays).

www.cornwallft.nhs.uk/community-specialist-palliative-care-services



Cornwall Partnership
NHS Foundation Trust



• Mount Edgcumbe Hospice • St Julia's Hospice •

Caring for our community

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



www.cornwallhospicecare.co.uk/our-community-services/

Hospice Stories



Why we Fundraise

Clare Bray—Community Services Officer for Cornwall Hospice Care visits the Marazion Group fundraising event to find out what motivates them

On a stormy Saturday in November, the Marazion Volunteer Support Group held their Christmas Coffee Morning at the Marazion Community Centre. The group are no strangers to organising events, but this was their first big one since the start of the pandemic.

Despite the dreadful weather, plenty of people turned out to support the event and enjoy a host of Christmas stalls, raffle, tea and mince pies. The group are celebrating 30 years of raising funds for Cornwall Hospice Care — some members have been there since the start and others have joined along the way.

It all began in 1992 with founding member Ann Don whose parents had both been cared for in hospices. Ann's mother had spent 5 weeks in St Julia's, which then was just 5 beds within St Michael's Hospital. Ann wanted to give something back for her mother's care and so decided to ask her friend Fran Philips to join her in some fundraising, and the group went from there. Fran was happy to join in as her mother had always been involved with St Michael's hospital.



1992...where it all began!

Thirty years on and the group is still going strong with a consistent 12-13 members. Joyce, another member of the group who was on the refreshment table on Saturday, said the hospice is such a big part of the local community. Joyce's husband spent some time in St Julia's Hospice 10 years ago and so Joyce feels it's fantastic to be able to give something back. Over the years the group has lost members, one of which, Margaret Rowe died at St Julia's, and so they all know how important the end of life care provided is to families and the wider community.

One of the stall holders on Saturday was Susan Collins with her vintage jewellery. Susan likes to support cancer charities as her daughter has been living with cancer for a number of years. Susan said, "This year feels particularly poignant as we know of younger people who have been cared for in the hospice. I like to support the fundraising group and being local I know a lot of families who have been supported by Cornwall Hospice Care".



Fundraising group founding members; Fran and Ann



Group members Joyce and Maggie



• Mount Edgcombe Hospice • St Julia's Hospice •

Caring for our community

Visit this link to find out more about fundraising for us...

www.cornwallhospicecare.co.uk/support-us/fundraising/

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/



Scan Me!



Are you an Unpaid Carer?

Would you like to take part in a “Text message” study by Falmouth University?



The research is exploring if mobile technology can help reach and understand issues relating to unpaid carers in a remote area like Cornwall

If you interested in taking part please text **CHC** to

07770 654 123

a return text will contain a link to on-line information and details of how to participate

If you don't have access to a mobile phone, a loan phone can be arranged, if you would like to participate please write to CHC Unpaid Carers Study , PO Box 340, St Austell, PL25 9HQ

Version 4 (15/10/21)

Sponsored by



Cornwall Partnership
NHS Foundation Trust

Health Research Authority ethics approved by
WELSH REC 6 (Ref 21/WA/0286)



• Mount Edgcumbe 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, or 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



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



Self-help pages: Resources for Lymphoedema, breathlessness, mindfulness & relaxation

Call 01726 829874 for more information or visit our website or scan here.



www.cornwallhospicecare.co.uk/our-community-services/

THE COVE MACMILLAN SUPPORT CENTRE



The Cove Cancer Support Centre

The centre opened in conjunction with Royal Cornwall Hospitals Trust and Macmillan to provide support for cancer patients and their family members through their cancer journey. We offer support where you can discuss any concerns you have, such as the emotional effects of cancer, its impact on relationships, advice on how to talk to loved ones, and many other subjects on living with cancer. We also have an excellent selection of booklets and leaflets to guide patients through their journey, including information about specific cancer types, various treatments, symptom control, diet, welfare and benefits, relationships, travel, living with, and beyond, cancer and local and national support agencies.

Other services include Finance and Benefits advisors, Counselling and Psychological Support, Nutrition & Dietetics, Physiotherapy, Support Group Hub and Workshops.

Please contact us on 01872 256363 or email thecove@nhs.net

Monday to Friday 9-5pm

www.royalcornwall.nhs.uk/services/cancer-services/the-cove/



• Mount Edgcumbe Hospice • St Julia's Hospice •

Caring for our community

Cornwall Hospice Care
Porthpean Road
St Austell

Telephone:

01726 65711

Email:

communications@cornwallhospice.co.uk

Cornwall Hospice Care has two hospices; St Julia's Hospice in Hayle and Mount Edgcumbe 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

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



Tracey Davy – Community Services Coordinator



Cornwall Hospice Care Community Services & Community Connect Team



Nikki Kelly – Community Connect Manager & Chair



Clare Bray – Community Engagement Officer



Helen Treleaven – Community Services Manager



Lollie Brewer – Community Engagement Nurse

Thank you

Next issue July 2022 – For submissions please email

communityservices@cornwallhospice.co.uk

WHAT MATTERS?

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