

Macmillan Report 2020



Age UK Cornwall & the Isles of Scilly & Macmillan Helping those affected by cancer



Community Helpline: 01872 266383

Transport Helpline: 01872 223388



www.cornwall-link.co.uk



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"Everyone knows someone who has Cancer, yet few of us know what to say and how to help Cancer sufferers and their families."

WHAT WE KNOW

In Cornwall around 3,200 people are diagnosed with cancer each year, with over 11,000 people on the cancer register at any time. The number of family, friends and carers then impacted by this is indeterminable, but almost everyone will know of someone living with, or affected by cancer.

It is known those with cancer are likely to be more susceptible to other health conditions with a number who will have other health challenges in addition to cancer. For many, their families, and carers, it can often be a challenge to access information and support that can ease some of the worry and anxieties that surround them, such as access to welfare entitlements and services that can support wellbeing. Age UK Cornwall and Isles of Scilly (AUK CIOS) has experience from their first phase project working with Macmillan that people affected by cancer need information in the right format at the right time, and guidance to support and encourage them through their individual journey. The apparent complexity of statutory and other services can be challenging.

Why we do it

People affected by cancer tell us they struggle to secure solutions without someone providing a navigation role to show the way and help find effective solutions.

AUK CIOS and Macmillan developed their partnership working to enable the Macmillan Locality Team and professionals, community groups and service users to converge their support around those affected by cancer.

The driving ambition is the creation of a strong foundation, for people affected by cancer, to access support through bespoke and person-centred on-line navigation. This offers a connector for all groups, communities, teams, and individuals.

We provide a guided conversation approach, that is safe, softer and more encompassing - helping to provide a golden thread that connects people to volunteer navigators, online portals and/or telephone support.

This has proved effective as it complements clinical and specialist cancer support - creating an opportunity for people to experience wrap-around accessible and consistent care.

This partnership has;

1) Created community pathways for those affected by cancer, linking existing provision via a single information point The Cornwall Link

2) Employed a Community Navigator and Volunteer Officer working strategically across communities to raise awareness and support skills in Cancer Support and Navigation

3) Up-skilled the AUK CIOS Helpline team and information services, improving bespoke personal support for people affected by cancer

4) Developed a cohort of community volunteer champions who contribute to the raising of awareness around cancer, creating navigators able to identify existing resources and support for those in their community affected by cancer

Our Model

The following diagram is a simple representation of the delivery model and how various aspects of support are intended to converge on those affected by cancer.



This programme model enabled our trained community navigators to reach **1284 people** affected by cancer.

The following outputs and outcomes for the programme were achieved:

- 1) **6 Macmillan Volunteer Navigators recruited and trained in the Community Hub areas; Newquay, St Austell, Bude and Truro.**
- 2) Increased number of agencies and networks providing support and services in the portal by **624 listings, with 41,254 page views.**
- 3) **Coached 32 volunteers and staff through Macmillan Community Navigation Training to effectively support 365 people in cancer care navigation.**

This led to a positive impact on individual's experiences of finding the right information or support, at the right time in the right place.

Community Helpline: 01872 266383

Programme Insights

- Those participating often fed back anecdotally success stories and the difference we made

“Dear Emily, Thank you so much for visiting our group of people & their carers living with a variety of stomas & other related conditions. Your talk was so informative & very much needed & welcomed. It’s surprising how much is out there for people to access who need it but also sad that so many people are not aware of what’s available - Thank you once again for performing such a vital service & doing such a good job.”

Mandy Rowe

**Coordinator & ostomist
Lanhydrock Ostomist Group**

- A network of trained volunteer navigators supporting local activity were engaged and trained to provide support in their communities. They were all very keen and willing to develop their knowledge and skills

- Our Macmillan Cancer Information and Support Community Hubs were made possible through our highly-valued and well-established partnership with Macmillan - enabling us to build on shared learning approaches and the experience that Macmillan gained in their wider work and partnerships.

- Working with communities is a key aspect of the hubs’ potential, providing; support and information to anyone who needs it; a safe space to access 1-1 help, volunteering opportunities, help, offering a central point where individuals and groups come together.

- Our [Cornwall Link website](#) is an established platform of community-based support and information - it has been expanded to include a mini-Macmillan ‘library’ and access to Macmillan’s online resources- this has proved invaluable as we move towards more frequent digital connections.

Age UK Cornwall & Isles of Scilly Community Hubs in Action



Dropping in at Newquay

Our work with Newquay, began at the 'Cornwell' Festival of Wellbeing; a day attended by community groups and health professionals keen to develop levels of support in the local area. The event included a combination of workshops, exhibitions, demonstrations, live music, and networking events.

This event led to the Community Navigator becoming a regular representative at networking groups such as Healthy Minds, where community and health professionals met together to encourage improvement of the information and support offer; for example the development of the Cancer Information and Support Drop-in from Newquay Library.

The library provided inclusive support to the community - creating an opportunity to reach families and individuals. The library staff engaged positively, welcoming everyone, and ensuring people accessed the service and help they needed.

Community navigator conversations were wide and varied, not only helping those affected by cancer. With comments such as **"Macmillan do such good work"** people felt able to approach and talk about a range of topics such as a homeless person enquiring about how to find a foodbank and get a meal. We were able to help. This open approach helps enhance the reputation of Macmillan and AUK CIOS

Dropping in at St Austell

The community navigator worked side-by-side with our volunteer at St Austell Library Drop-in. Our sessions included interest from families, who attended for many reasons, such as: the Lego Club; individuals collecting library books; work, and other health professionals.

Our Inclusion Matters Community Coach, Tamsin, joined us at one of the Drop-ins engaging with

people who stopped to chat about our services and learn more about how the information and signposting supports people affected by cancer. **Working together, we shared the space with The Royal British legion and often directed clients to them and them to us.**

"The library staff were so welcoming and the relationship we built created a centre of trust for those attending the Drop-in service."

**Maria,
Community Navigator**

"It was great to talk to such a wide representation of people and inspiring to hear their dedication to making a positive change for Newquay"

Newquay attendee

"I wanted to understand their journey, the clinical language they hear and psychological barriers that hinder cancer sufferers and their loved ones, so that I can do more in my role at Age UK C&IOS and in other situations"

Volunteer



Working with those affected by cancer



We work closely with other partners and our internal teams, such as our Social Prescribers, offering client-centred support that brings a wrap-around service of professionals to help provide a pathway of options for those affected by cancer.

This approach has enabled us to reach many people affected by cancer, each with their own unique story and set of circumstances, yet all united in a need for information and support as shown in the case studies below.

Skin discomfort following cancer treatment

A lady was referred to a Drop-In session by a Social Prescriber, as she was experiencing some discomfort around skin conditions and creams following her cancer treatment. A confidential conversation took place, and she was shown how to access information about coping with associated side effects and symptoms, and how the online Macmillan community site works.

The lady was informed of events at The Cove and was interested in finding out which creams are favoured by The Cove and would be available locally. Contact was made with the local Boots pharmacy who confirmed both a Macmillan trained Pharmacist and Beautician were available. The lady was pleased to have been able to resolve her difficulties so quickly and effectively. **It meant she was able to enjoy a better quality of life**

Maintaining wellbeing and maintaining your Garden

A lady affected by cancer used to find pleasure working in her garden but was finding it increasingly hard to continue. **She had seen details of the Community Hub on our website as well as [information about our gardening service](#).** Being so fond of her garden she was keen to secure a reliable and trustworthy gardening service from a reliable source; such as Age UK C&IOS.

We were able to assure her that our gardeners all have satisfactory DBS checks and shared that they encourage the person whose garden it is to be as involved as they can. **She stated this is what she was looking for and we were able to link her with the gardening service.**

Establishing trust leads to a fuller understanding

The same lady was comfortable with our approach and started to open up and talk about her health. Respecting confidentiality, she was happy to share that she'd had an operation for a benign brain tumour and was experiencing fatigue and lack of energy as a result of treatment. This was why she needed help with her garden.

Continue overleaf

"Thank you for your contact and for your support when we met earlier today. I am going to contact the cinnamon trust as you suggested I'm really grateful for the support and listening ears."

Thanks again! Keep up the good work!" Megan (attendee)



Establishing trust leads to a fuller understanding

Due to a bereavement, she was also struggling with house maintenance, **so we linked her to our helpline for information about Home Support.** She mentioned she was having to attend Treliske Hospital for a hearing test and it was discussed as a possible opportunity to attend The Cove - finding the right support for fatigue and tiredness. We also mentioned that she could get a nice lunch or cake which appealed to her. Travel and parking were discussed, and the best option identified.

Learning from those we support

She shared information about one of the Macmillan Support Groups she attended and told us how positive her experience was. We thanked her as this would help us point other people to that particular group. www.cornwall-link.co.uk

Support those throughout the many stages of their journey

One individual we supported had been bereaved many years ago, but questions still lingered. They hadn't realised that both the Macmillan Support line and The Cove services could help, even though she herself did not have cancer. This individual had experienced a series of life challenges, including a significant bereavement, resulting in poor mental and emotional health.

Our navigators find bereavement can create emotional conflict and difficulties moving on. People can feel unsupported and alone, even feeling life is no longer worth living.

Through our partnership we are able to build an effective rapport for people who experience this unresolved grief and make successful referrals to Macmillan Professionals and The Cove.

A Snapshot into our activities

The Eden Christmas Fair

Our Community Navigator attended The Eden Project to join local businesses, Macmillan volunteers and Macmillan professionals to raise the profile of Macmillan, the partnership, and the support available to those affected by cancer.

It also acted as a pop-up drop-in with individuals seeking help and being supported.

We were able to promote The Cornwall Link platform both for potential support groups and organisations to register their offer and for individuals and community leads to access as a directory of support.

Holsworthy and the community

We attended their sprint networking event which enabled us to;

- Explore our commonalities and differences
- Gain a shared understanding of the needs of the community
- Build community capacity, reduce social isolation of our population and practitioners
- Hear people's stories

Interestingly, an activity revealed that between all the Health and Public Service professionals and local community representatives in attendance we brought 778 years of experience to the event!

Liskeard - Methodist Church and the Junk Food Cafe

Our Community Navigator and Cancer Information and Support volunteers worked with the church and café to reach out to people - providing a day where they could get a free lunch.

Combining these local community assets drew people from all parts of the community, including rural areas, those with housing issues, isolated and lonely individuals, families on low incomes and the staff and volunteers of the church. We were able to provide information and signposting, but what we found was most needed was that all important listening ear. At a subsequent drop-in we arranged for other service representatives to attend; **introducing them to Sam Hudspith, Macmillan's Volunteer Services Manager Southwest. Helen Gardner, the Liskeard Methodist Church Family Worker was keen to take up the offer of Cancer Awareness training for the staff and volunteers. Working alongside our Community Navigator, our Age UK C&IOS volunteer also played a key role, improving the support available to those affected by cancer.**

There were many who were linked with support, this ranged from dog walking to accessing Information Technology. One simple situation with a profound beneficial impact - **an elderly**

lady just wanted someone to talk to as her grandson was in remission, she was still feeling the impact of losing her late son who suffered from schizophrenia. We were able to link her up with professional and peer support.

Truro - The Cove

We developed an effective partnership approach - working with Kathryn Radcliffe, Manager of The Cove Macmillan Support Centre and her teams of physiotherapists, Macmillan Clinical Psychologists, Macmillan Citizens Advice professionals and The Cove's Macmillan volunteers. **Our work with The Cove has improved our understanding of the support available and the challenges many affected by cancer face. We were able to come together and implement some collaborative solutions.**

The Cove explained how difficult it was for some people to access their support, even taking days or weeks to enter the building. We felt that if there was a broader offer of support, such as from AUK CIOs, some may feel less nervous approaching and appreciating the alternative advice as an incentive to take those first steps.

Bude - Parkhouse Centre

This was the first Health and Wellbeing event run outside Devon by North Devon Hospital in Barnstaple. It provided an opportunity to bring cancer patients together to find out about information and support available across the wider community. We attended with members of Macmillan and were able to add value to the event as well as legacy information and routeways to support;
- information and advice relating to health and wellbeing,
- access to local resources and services
- how to connect with local and national charities, both clinical and non-clinical,

We also worked with several individuals who are now able to facilitate interaction between people affected by cancer and networks of support.

Age UK Cornwall & Isles of Scilly

Our Training



We worked with Macmillan to develop and provide training as part of our partnership strategy. The intent is to improve access to support for people affected by cancer across the county.

Navigation Training

A typical Cancer Navigation Training Day includes:

An introduction to Cancer: Covering some of the basic clinical elements of cancer, improving understanding of key medical terms and providing an overview example of a cancer journey.

Psychological Impacts of Cancer: Exploring the many thoughts and feelings that can be provoked by cancer both for the person affected and those around them. Thinking about ways to manage these.

Difficult Conversations and Boundaries: This element of the training is designed to reduce fear and improve confidence to be able to talk about cancer, including: **helpful phrases, listening techniques and strategies for those affected by cancer to look after themselves and others when difficult topics arise.**

Information and Signposting: To learn about sharing and finding information to support people affected by cancer.

An opportunity to promote resources, such as: our community website, [Cornwall Link](#); [Be.Macmillan \(online\)](#); [Macmillan Cancer Support \(online\)](#); The Cove; our Macmillan library and details of our Drop-In sessions, where we provide tools for people to draw upon.

Trainers come from both organisations and create a strong team ethos, adding shared values to the offer. **This approach enables us to gather feedback, share learning and implement changes that will ultimately, improve our Navigator training package.**



Our Community Navigation Training - 17 Staff and 17 Volunteers attended.

Even better if

- ✓ **Reflective downtime** – making sure candidates had better breaks.
- ✓ **Speeding up on practical concerns** – re-focused the navigation section.
- ✓ **More time on communicating** with family who are afraid for those they care about – we gave more time for attendees' individual stories.
- ✓ **Allowing more time to cover all the areas** – we intend to run peer group workshops to share more information and hear your stories and needs.

Ideas for the future

- ✓ **Follow up sessions** to develop and reflect on skills and practice of using Macmillan Learn Zone, sharing experiences.
- ✓ **Embed Macmillan awareness** into Age UK volunteer journey
- ✓ **More focus** on family members and younger people with cancer.
- ✓ **Discussion topics:** future/upcoming developments in cancer support. Further discussion with attendees and how they can assist Macmillan.
- ✓ **Helpful tips** 'e.g. What to say' in a support pack

What we have learnt

Training has increased confidence to support and talk to people affected by cancer - but would benefit from future Macmillan updates to increase knowledge and development.

The information supported both staff and volunteer roles equally.

It provided an opportunity to **learn about other's roles** and the intentions to support people affected by cancer.

A safe space is essential and we created this to share cancer stories and feedback.

A knowledge of clinical terms was increased, as did **understandings of the journey a person affected by cancer takes**, which helps to break down barriers.

Giving people a platform to be listened to was key. Making sure each person was made to feel welcome and that equality and diversity was respected.

Highlights from our Q&A

Q. Have you been able to make use of the training in your role?

A. 100% said 'Yes'

Q. How have you used the training?

A. Both in my personal life and professional work.

A. Sign-posting to the COVF

A. Offering the 'Cancer at work' resources

A. Volunteer support to the Community Navigator at the Liskeard Hub

A. I have been able to use my knowledge in talking to Inclusion Matters clients affected by cancer and signpost them appropriately when required.

Q. Have you felt more confident when having conversations about cancer

A. 100% said 'Yes'

Q. Which areas of training have you found most useful in your role?

A. Awareness of the range of support that Macmillan offers to everyone with cancer

A. I found the discussion about boundaries interesting, and as a result we now include this on our induction training, albeit in a general sense regarding our involvement with people who use our services.

A. The knowledge about helping to understand what those affected by cancer may be experiencing and how this affects their lives.



***“Thank you for an excellent, informative session.
I would be open to any further training, information
sharing and results from the Q&A”***

This table shows the anticipated and requisite outcomes along with how we would know.

Outcomes	Evidence
Trained volunteers	Volunteer for each locality - good spread
Supporting individuals	Training, 1-1 reviews, calls, follow-up's
Local engagement	Reinforcing where to find support & how
Signposting	Volunteer role description
'Listening ear' - friendly	Case studies & vignettes
Facilitate support for wellbeing	Case studies & vignettes
Simple, respectful, comfortable – reliable, dedicated	Case studies & vignettes
Understanding what's available – how to access services	Case studies & vignettes, Cornwall Link listings & stories

Working co-productively with all involved we were able to continually evaluate the volunteer training offer and revise it - by the end of phase 1 we had made significant steps in generating awareness and enriching our provision, some of these steps are summarised below:

Overhauled the on-boarding process to better suit the changing needs of the organisations and services involved.

Staff and volunteer Induction Days were revised to identify who would appreciate Macmillan Training.

Created new 'Volunteer with Us' marketing materials with Age UK Cornwall and Macmillan logos.

Co-designed a Volunteer Satisfaction Survey - 2019

Volunteer engagement events were held to help us gain a deeper understanding of some of the themes behind the statistics and comments in the Volunteer Satisfaction Survey. These events were held in the evenings, at locations across Cornwall to maximise profile, reach and engagement.

Purchased new promotional items with joint logos to display the literature and act as a visual reminder of our partnership.

Volunteers were keen to know more about and sign up to Macmillan Navigation training – especially our TAP (Transport Access People) drivers who take clients to and from their oncology appointments.

Creation of a Volunteer Review form - providing an informal 1:1 discussion between service managers and/or Volunteer Officer and their volunteers. Both parties are encouraged to explore the volunteer's experience, training and future plans.

The availability of Macmillan training is listed as a future option for the volunteers should they wish to pursue any personal and/or professional development

Introduced a Newsletter that included a 'Macmillan Update' which gave more details about the training and support available. The newsletter provided a medium to highlight our partnership and the work undertaken for those unable to access digital sources.

Established South West Network Group Meetings, where we shared knowledge and experience with other Age UK's in the South West region.



Age UK Cornwall & Isles of Scilly

An overview from our Volunteer Officer



Our Macmillan Volunteer Officer wrote a report that provides insight into their role, contribution, and an indication of the impact of the project overall. It would be impossible to include the fullness of activities and the anecdotal evidence of just how significant the domino effect of this work has been.

“Volunteers are at the heart of this project and essential to its success”
Sam Hudspith,
Macmillan

We are Macmillan

As a newly appointed Volunteer Officer, my involvement with Macmillan started part-way through the contract term in June 2019. **My task was to improve the volunteer on-boarding process, journey and exit procedures whilst integrating our partnership with Macmillan.**

I received the initial ‘We are Macmillan’ and Macmillan Community Navigator training. These gave me a better understanding of not only the organisation but also what and how support for people could be accessed, and when speaking to people affected by cancer, how to approach those all-important but difficult conversations. Macmillan also supported me to access relevant training in ‘Volunteers and the Law’ and a ‘Volunteer Management Conference’ in London. These events have shaped my ongoing work with volunteers & staff, as I have exemplified here.



Supporting volunteers

Volunteer 1

- **Following a serious accident, recognition that this volunteer’s confinement to home was the biggest threat to his recovery.**
- **Instigated wraparound support for his mental and physical wellbeing involving a number of our service leads and managers.**
- **Resulted in his full recovery and return to volunteering with even more enthusiasm, including adding Macmillan Drop-ins to his volunteering roles.**
- **Having understanding of his needs, ensured that at the start of the lockdown in March, this volunteer was immediately highlighted as being a volunteer who would need additional support.**

Volunteer 2

- **As a way to improve her health and wellbeing, a volunteer who had cared for her husband on his cancer journey was referred to volunteering by one of our Social Prescribers.**
- **This volunteer applicant became emotional when Macmillan was discussed at her Induction day - however, with gentle encouragement, time and space she was able to say how grateful she was to Macmillan in being there to support not only her husband but herself, during their most difficult times.**

Volunteer 3 - TAP Driver

- **On hearing about our partnership at a Volunteer Engagement Event, a TAP driver discussed that his daughter was on her cancer journey with the best possible outcome.**
- **He said that he was humbled by the work of Macmillan and was proud to be a part of an organisation that had decided to work with them for the greater good.**



An overview from our Volunteer Officer

Supporting volunteers Volunteer 4

- **This volunteer had been supporting a client over many years and throughout the client's cancer journey.**
- When the client passed, the volunteer was bereft and in need of emotional support.
- **Working across the organisation, we were able to support her in her time of need through visits and phone support.**
- Answers were found to her most compelling questions regarding some of the care that the client had received, and, why certain decisions were made.
- **Our partnership enabled a clear route for the manager to access general information which informed her responses and reassured the volunteer.**

Volunteer 5

- Service managers are encouraged to inform the Volunteer Officer of any significant health and wellbeing concerns that arise with our volunteers.
- **This volunteer was on her cancer journey. Following a support call an appropriate card with contact information was sent.**
- Further telephone support calls encouraged her to attend a social event at Newquay Day Centre, but she was worried about how she now looked 'unrecognisable'. Arranged a follow-up call from the Day Centre Manager to gently encourage.
- **Ensured the volunteer had family and external support - reminding her of our Macmillan partnership should she feel either organisation could do more.**

Steps we have taken for Deceased Volunteers

- Encouraged notification from service managers.
- **Sent sympathy cards with a personal message of regret and thanks for their loved one's service to our clients.**
- Where appropriate, attended funerals of deceased volunteers or arranged for senior management to stand in.
- **Support offered to bereaved partners/families**

What I have learnt

Whenever and wherever I have mentioned the name Macmillan, I have been invited to have an insight into a person's cancer journey, either their own or a loved-one's. **I always feel humbled that they feel safe and confident to talk with me and share their experience.**

I am proud to wear the two lanyards (Age UK Cornwall and Macmillan). I feel it is a visual reminder to myself and a visual prompt for staff, volunteers and the wider public, that I am approachable, professional, listen and if needed, have some knowledge of where to signpost for further support.

The methods and measures put in place have allowed us to embed our partnership in all processes that involve staff and volunteers. **Today we say, 'it's just what we do', having Macmillan by our side.**

"Your partnership with Macmillan was highlighted and contributed to your Bronze Award 2019"

Healthy Workplace Cornwall



Programme Summary

This first phase of our work with Macmillan has been positive and it set in place firm foundations for the next phase, which includes the appointment of a Programme Coordinator and two Community Navigators.

Our ambition is to continue the development of the partnership and progress of the Navigator training. Our training programme will be embedded throughout our organisation, increasing confidence and skills of our staff, volunteers, and our IM partners. **We will embed the core messages, supported by appropriate training, making it an integrated part of everything we do.** To help create more resilient communities, this training offer will be made available to community groups, thus increasing the support for people affected by cancer. Our Community Navigators will build bridges between clinical, community and individual needs, to develop a more joined-up approach.

Our Strategy

Our aim is to be more responsive to the community's needs, engaging and supporting localities to change their culture, and create empowered and compassionate communities.

Based on our testing to date, there are a potential 6 interested hubs across Cornwall, where we intend to train, mentor, support, and shape a cohesive network of navigators. **We will wrap support around these hubs by connecting learning and support, offering digital tools and shared learning opportunities.**

We will increase our reach by diversifying engagement and learning opportunities through our digital strategy and e-learning package. This, in turn, will increase accessibility and cater to different learning styles, **supporting people in remote and rural areas and those with other long-term conditions.**



However, at the time of writing this report, the county, and the whole world beyond has been impacted by the Coronavirus (Covid-19) pandemic has meant that we are reviewing the way we deliver our service. **It is increasingly clear that services and organisations will need to reshape for the future, with honest and practical solutions to be found and implemented.**

Whilst we had to make the difficult decision to temporarily close the Macmillan Information and Support Drop-in sessions, we have implemented an offer of a call-in for anyone affected by cancer who needs information or signposting, or that all important listening ear.

With the excellent strong and established partnership we have with Macmillan we are confident we will establish a revised delivery model that not only responds to the needs of those affected by cancer but, reflects the spirit of the partnership and honours the outcomes.



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With thanks to our supporting partners, fundraisers & volunteers, who all add so much to improving the wellbeing of older people in later life

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