# Living Well Macmillan Report August 2018



### This report outlines who we are, what we have achieved and the difference we have made for people affected by cancer.



"With all my heart & gratitude, I say thank you to you and the Project, Living Well Macmillan."

Quote cited from Maria's Journey

# Age UK Cornwall & Macmillan You know us already

# Age UK Cornwall & The IoS

Our mission is simple, we aim to take the positives of ageing and minimise the challenge, where we can, through prevention, support and working tirelessly;

# to improve the wellbeing of people in later life.

# **Our Principles**

The following principles underpin what we do and provide direction to our operational priorities, but they also act as a moral compass for the way we behave.

We are inclusive – people in later life are not a separate group and do not all have the same needs and ambitions. Later life is, hopefully, the future for all of us.



We are respectful – we are all human beings deserving of respect. Someone who is 10, 20 or 50 years older than someone else is not a lesser person and nobody, however young or old, should be patronised.

We are positive - we focus on the positive aspects of later life and show what's good about age. We can't always do everything we used to, but there are things that we can do now that we couldn't before and things that we know now that we didn't know before.



We are truthful and realistic - we are honest, even if things are difficult and if we get it wrong we will be the first to hold our hands up. We talk openly, directly and truthfully and we will not turn people into objects of sympathy to raise money or make a point.

We offer solutions - we develop and provide support that improves our quality of life. We use donations, fundraising and legacies for universally accessible services that we do not want to charge for such as; advice, information & befriending. We support people by being resilient in times of change and facilitate services that let individuals support themselves.

# **Macmillan Cancer Support**

Being told 'you have cancer' can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you're still you. We get that. And, after over 100 years of helping people through cancer, we get what's most important: that you're treated as a person, not just a patient.

It's why we'll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We're here to help you find your best way through from the moment of diagnosis, so you're able to live life as fully as you can.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

# Age UK Cornwall & Macmillan Living Well Macmillan

## What we do

Since 2015, Age UK Cornwall & The Isles of Scilly and Macmillan Cancer Support have been working together on the Living Well Macmillan project.

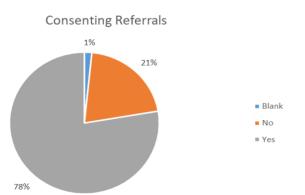
# Our partnership supports the community, coordinating holistic solutions to local

**challenges**. Our objective is to deliver a wide menu of services & opportunities to support both the needs of people affected by cancer, and people who need end of life care. The Living Well Macmillan project **is unique, in being connected at both a strategic and grass roots level.** This partnership and collaboration ensures that the project has a greater engagement and reach within local communities, helping the **right people at the right time and developing innovative results.** 

We have seen tremendous support for this project within the community, working with a plethora of **compassionate groups and GPs to develop effective goal setting and care plans that put the needs of an individual first.** 

# The difference we have made

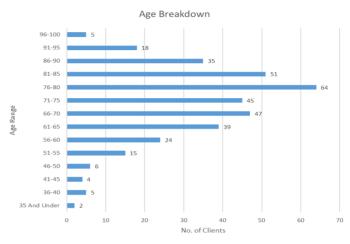
The project received **556 referrals**, from **24 GP** surgeries in Cornwall, resulting in **4,839 contacts**.



\*59% of individuals were female (213) & 41% were male (147) \*432 clients joined the project, representing 78% total referrals \*Our Living Well Macmillan Coordinators worked with GP's, community groups and stakeholders mainly in West Cornwall.



We place the **individual at the centre of everything we do**, we are interested in engaging the whole person through a range of **physical**, **emotional and mental** supportive tools. Throughout this project, we have supported individuals from a wide age range, from under **35 to nearly 100 years old**.



# **Heidi's Story**

Heidi is a sixty year old widow, who made a self-referral into the Age UK Cornwall and IoS Living Well Macmillan Project. Heidi's husband, at the time, was receiving end of life care due to pancreatic cancer. Heidi's husband was still living at home with Heidi caring for him 24 hrs per day.

The couple were struggling financially and our Living Well Macmillan Coordinators were struck by the sadness & complexity of her situation. Supporting Heidi emotionally and practically in the months to come was going to be as equally important as the support needed for her financially. Heidi was selling household items to pay outstanding bills and struggled with the benefits system. After the passing of her husband, her grief became all-consuming, impacting her health negatively, with panic attacks and anxiety becoming a regular occurrence.

Our Coordinator was able to help Heidi gain financial support through Personal Independence Payments, seek advice through the Cove Macmillan Support Centre and apply for a Bereavement payment scheme. Over the next few months we helped Heidi make contact with the local community hall, a job support agency and we researched local activities and opportunities. This helped Heidi to reconnect with people and find the right support available in her area.

Heidi has overcome many obstacles through her own determination and in a very short time has boosted her selfesteem and positivity. **We feel privileged to have shared this journey with her.** 

# Age UK Cornwall & Macmillan How we do it?



Cornwall &

### **The Journey**

Following the referral, our process is to complete a guided conversation, which helps facilitate discussion and understanding around the topics that **really matter to the individual we are supporting**. From these results, we can then develop a unique package of care which identifies the aims & goals of the person in need.

It is important that we **identify community resources, signpost and navigate to the groups, activities & networks available in a persons location.** Only then, can we begin to put the correct steps in place for ongoing practical and emotional support.

#### We recognise that everyone is different so our response will vary from person to person. Our Living Well Macmillan Coordinator helped by:

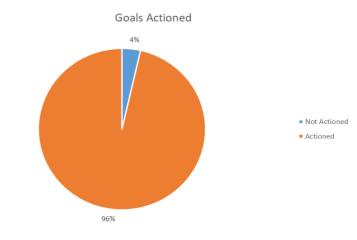
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- visiting people at home, helping to identify needs and how we might help.
- listening to the story of the individual and putting their needs first.
- providing support with getting benefits, grants
- , and further advice
- facilitating access to social care and health , support that you want.
- signposting to the community and services that can support ongoing needs.

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connecting people to the right health services, surgeries and hospitals.

- m / supporting goal setting and practical tasks
- , helping people to join their community,
- develop friendships and identify support networks.

Since the project began, we have set **over 1,100 goals. 60% (662) of these goals have been achieved on the 1st day of contact.** This has meant an immediate increase in wellbeing, and a reduction in loneliness & isolation, once the individual has completed the initial assessment with a Living Well Macmillan Coordinator.



\*96% of goals set were actions (1103) \*The mean number of goals set per client was 2.9

# Age UK Cornwall & Macmillan Your Views

"It was so helpful to have someone to discuss money worries with and get pointed in the right direction. Just knowing you are there makes a huge difference. My mother was so excited when I told her she was entitled to benefits, easing the financial pressure meant the world to her and was one less thing to worry about" Quote from Cathy's story

#### **The Volunteer**

We rely on the **skills, expertise & knowledge** of Volunteers for all our services, whether it is providing a friendly ear or offering more practical and ongoing support, every Volunteer we work with is valued and has played a key role in the Living Well Macmillan Project. "Volunteers are vital to bridging the gap" Tracey Roose, CEO Age UK Cornwall & the Isles of Scilly

# The following is a statement from one of our fantastic Volunteers:

"I applied to the Macmillan branch of Age UK Cornwall & The Isles of Scilly as I wanted to work with those whose lives were forever changed by cancer and with those who were facing their own mortality. As a society I feel that often we are death denying and yet I have always felt open to the issues surrounding the subject, so I thought I may be of service and support at such a challenging time in a persons life."

"Following an informal interview with the friendly, compassionate Age UK Cornwall Macmillan Coordinators and the obligatory police checks, I was accepted into the support team. The Coordinator of our team is very supportive and understanding, I feel I can be completely open and honest with her and she responds promptly with any queries I might raise."

"Once I got to know the team, I very quickly had my first referral. For me personally, it was an honour to be invited to accompany someone on their journey at such a devastating time in their life, whatever the outcome might be. To sit quietly, listen to their hopes and fears, hold a hand or give a hug, and be a constant in their ever- changing landscape is so rewarding and such a privilege.

Cornwall &

The Isles of Scilly

In my opinion the role does require a level of commitment and that commitment should not be taken lightly, as a solid loving relationship between an individual and a befriender can feel very important at such uncertain times."



# The Individual

These are a small sample of responses, reflecting the continuous and collaborative work supporting people affected by cancer.

"We really need people like you, who will see things through and really care about us."

"Thank you for coming to see me today. It was lovely to meet you and you made me feel so much better. I can now go back shopping for new walking boots and a cooker, I want to build myself back up and get healthy again, Thank you SO much!"

Community Helpline: 01872 266383

Cornwall Link: www.cornwall-link.co.uk

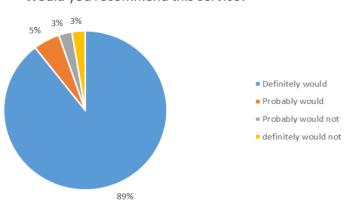
# Age UK Cornwall & Macmillan Your Views

#### **The Individual**

"I've been invited to write a few words on the Age UK Living Well Macmillan project. I have COPD. Cancer has a higher profile than COPD but I sneaked in under the radar due to my tenuous connection to cancer when my dear father died of it, the common ground being that both diseases can be regarded as terminal, although survival rates for cancers are far more optimistic these days, whereas COPD has only one eventual outcome.

"But moving on from such morbid and negative aspects to concentrate on the positives, support from Age UK Cornwall & Macmillan means life doesn't need to be faced alone any longer and I've been fortunate enough to be 'issued' with Joy, a lovely lady who visits once a week to chat and share my fears and concerns, although we are more inclined to cover topics like travel, world events, theological discussion of faiths and the price of fish. I am most grateful for the visits from Joy, without whom I'd not see a living soul for a week or longer so many thanks Age UK!"

"This is the first time I have been outdoors in some time. It is so magical, I will go to sleep dreaming about it and ask my husband to come next time, he could take pictures and I could watch the world go by"



Would you recommend this service?

\*94% of individuals would recommend this service.\*90% of individuals found the project extremely or very helpful.



#### What have you found most useful?

As part of our evaluation and assessment of impact for Living Well Macmillan Project, we asked participants **which element of the project had been most useful and what could be improved;** the overwhelming responses were positive:

#### \*I was helped with my finances, the Coordinator saved my life. Without her I don't know what I would have done.\*

\*The worker helped me feel better within myself and cope with everyday things, also she helped with form filling as I get anxious when doing so.\*

\*Gardening service, and the caring way I was listened to.\*

\*Shout about the service and provide more advertising that it exists!\*

\* The extreme kindness and understanding of the situation- i.e. loneliness and frustration of not being able to do the things you used to. Examples include - walking, talking, gardening, just going to the beach for a walk. Hoping to join more activities in the future.\*

\*A great help was the Information and Advice volunteer, helping me with my blue badge which had been refused, plus my attendance allowance.\*

\*Just needed to have that personal touch that was difficult to find from NHS element (due to their being so stretched no doubt). The knowledge you can call on someone whatever time of day. Even just for reassurance.\*

\*Signposting from the local doctor would be hugely beneficial\*

\*Having someone to talk to on a one to one basis, and to guide you through the red tape etc.\*

\*Just being there helps people, me included\*

# Age UK Cornwall & Macmillan Learning & The Future

Some key steps emerged during the project, which we have learned from, and will review as we approach the next phase of our collaboration with the Macmillan team.



Our learning was focused on the **development** of relationships with the range of people involved in the lives of those affected by cancer. Conflict and misunderstanding can arise when we do not understand each of our roles or approach. For individuals it can be very confusing having different people visiting who all appear to be doing similar things.

Fortunately, we worked through these issues, identified solutions and ensured we were working collaboratively with others to reduce the stress and confusion for participants. This was due to the commitment of all partners, volunteers and staff, ensuring the vision of supporting individuals on their journey is the best it can possibly be.

#### **Actions:**

- Regular discussions with external colleagues to understand one another's priorities and approach to Cancer support.

- Ongoing discussion with external colleagues to understand and appreciate one another's challenges, pressures and limits.

- Development of trust across services to enable a collaborative approach.

- Regular meetings to discuss issues, case studies, reflect on practice and improve approach e.g. referral process.



- Identify support for the team to reduce the risk of burnout, enabling opportunities to off load and share the intensity of the work.

- Understanding and developing the contribution of volunteers. To provide person centred, ongoing support to help build confidence and connect people one to one or to groups in their communities.

As the project progressed, we identified the need to keep boundaries in place, to ensure we did not get too involved and could step back from situations to review and reflect. This was challenging at times due to the intense and often emotional nature of the support and the complex situations people were living with.

The discussions with multi-disciplinary partners helped us to **develop our approach and ensure we were objective and reflective.** This has been a most welcome support to the project and one that we are keen to maintain and develop further as we progress.

Upon reflection, **some of the key support skills for individuals are compassion, sensitivity and at times a dose of humour**. Many of our volunteers and participants have shared their stories, personal feelings and fears during this project, but they also share their laughter, joy & appreciation when times are most difficult.

Cornwall Link: www.cornwall-link.co.uk

# Age UK Cornwall & Macmillan The Future

Macmillan Cancer Support and Age UK Cornwall & Isles of Scilly's partnership is to go from strength to strength with the roll out of countywide support for older people living with Cancer.

The partnership continues to tackle loneliness, isolation and improve access to community support for Cornwall's older population who are affected by cancer but from July 2018 we will aim to reach even more people with a new model of support.

Featuring a new Community Navigator and Volunteer Experience Facilitator, funded by Macmillan Cancer Support, the re-launched initiative will utilise volunteer 'Community Champions' and the online portal Cornwall Link to create a network of support across the county.

Jacqui Hodge, Macmillan Cancer Support, Partnership Manager for Cornwall and the Isles of Scilly explained **"I'm so proud of what has been achieved to date with our partnership with Age** *UK Cornwall and the Isles of Scilly, we've learned so much and reached a huge number of people who were really struggling with challenges such as isolation and depression exacerbated by their poor health. I'm looking forward to watching our new initiative roll out across the county and seeing how many more people we can help."* 

Since 2015 Age UK Cornwall and Isles of Scilly and Macmillan have been working together on the Living Well pilot project. Since then they have reached and supported 360 individuals



living with cancer and their families. Helping with physical, emotional and practical issues. Support has ranged from providing companionship; help accessing support groups and social activities; and solving practical problems such as finding someone to walk their dog when people were unwell or having treatment. As a result of this support, GP appointments and admissions to hospital were reduced by empowering people to connect to others and access support services in the community.

The new model of support will continue to offer companionship, social opportunities and practical help but will move away from one-toone sessions so that a greater number of people can be reached. It will empower Community Champions, volunteers and utilise Cornwall Link to connect people to wider range of local support options.

Jacqui added **"Moving on from one-to-one** sessions and towards a network of volunteers and people-focused digital support tools such as Cornwall and Scilly Link will extend our reach considerably."

Tracey Roose, Chief Executive of Age UK Cornwall and Isles of Scilly added **"Isolation and loneliness can affect anyone at any time. For people affected by cancer it compounds an already challenging time, impacting on mental and physical wellbeing. Our partnership with Macmillan focuses on a shared ambition to make a difference to the lives of people in Cornwall and the Isles of Scilly"** 



