

Sue Ryder

End of life care in the digital age – extending Sue Ryder’s advice and support

Elinor Jayne¹

¹ Policy and Public Affairs Manager – Scotland

Background

Sue Ryder’s vision is to create a world where everyone has access to personalised and compassionate care. Through our charity partnership with Morrisons, we have a specific aim to provide end of life care to more people across the UK than ever before by 2017. As a national organisation providing care across England and Scotland, we are looking at ways to extend our end of life care services beyond our physical locations. Supporting people digitally through an Online Community (sometimes referred to as an ‘online discussion forum’) was recognised as one way to do this.

Why an Online Community?

In our experience, most end of life support, advice and co-ordination services are provided during working hours only. Indeed, a Sue Ryder Freedom of Information request showed that only one of Scotland’s health boards provides a comprehensive advice and support service on a 24/7 basis. Yet 50% of calls to Sue Ryder’s 24/7 co-ordinated advice and support service in Bedfordshire are made overnight.

Not only is it a reality that people die at home overnight and at weekends, but this is also the time when people who are dying, their families and carers, can feel most isolated and scared.

“I was at my wits’ end the other night at 12.30am, until I logged on here and realised I’m not alone.”

Sue Ryder Online Community user

Bereaved people often feel they do not have adequate support following the death of a loved one. Yet we know that if people have the chance to talk about bereavement and have access to support and advice, they are likely to recover more quickly. Research conducted on our behalf by Census Wide with 2,053 respondents found:

- People who had others around to talk to during bereavement felt better, on average, after two years, one month and four days following the death of a loved one.
- People who didn’t have anyone to talk to grieved, on average, for an additional eight months, three weeks and five days.

Time taken to feel better after bereavement

People who had someone to talk to

764
DAYS

People who had no-one to talk to

1133
DAYS

There is clearly a lack of support and advice for people who are dying and for their loved ones, as well as a lack of support for people who are bereaved. This led Sue Ryder to set up our Online Community, which launched on 2 June 2015. The launch was supported by a PR and marketing campaign, and there has been ongoing activity since then to raise awareness of the community nationwide.

“Finding this site has been a godsend. It’s comforting to know you’re not alone, there are others here who are going or have gone through the same desperate grief/pain. I’ve learnt grieving is a natural process, it has no rules, conditions or a time limit; unfortunately, family, friends, colleagues don’t understand that.”

Online Community user

How does the Online Community work?

The website is split into two sections. The first is a community for people receiving end of life care, and their families, and for people who have been bereaved. It is designed to connect people with similar experiences. Bereavement support volunteers from St John’s Hospice in Bedfordshire are also on hand to offer experienced advice and emotional support. No medical advice is given via the Online Community. It was initially anticipated that specialist palliative care nurses would also provide support, but in the community’s first year there has been much more demand for bereavement support.

The second section of the website is an advice section that contains expert answers to frequently asked questions about things like going on holiday, making a will, what it is like when someone is dying and how to cope after they’ve died. As well as FAQs, this section contains people’s stories and signposts users to further information and other expert organisations. Information contained in the FAQs is evidenced, peer- and user-reviewed, and is sensitively and clearly expressed. The information will be reviewed in April 2017 to ensure it is still accurate and up to date.

“We’re in the last stages and information has been a real help to me. Not from anywhere, as that can become scary, but from a few reputable sites.”

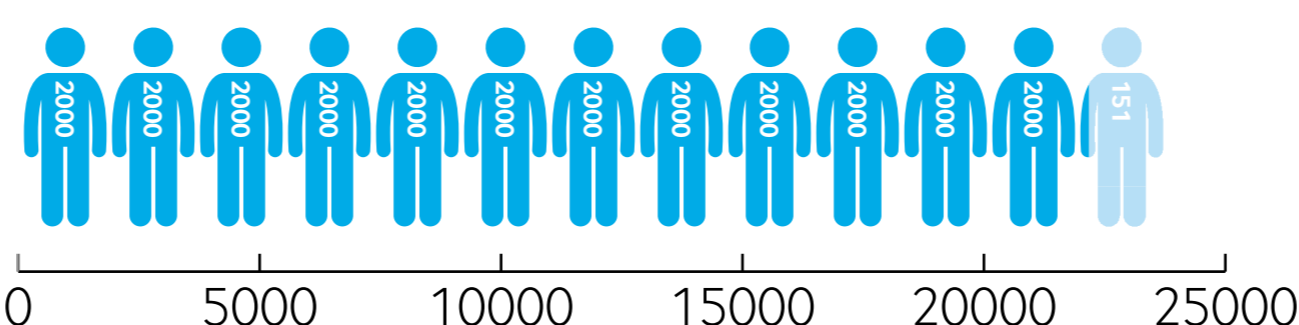
Online Community user

All the conversations on the community can be accessed and read by anyone. This means that people who are not ready to share their experiences or ask for support can still read about other people’s experiences and see that they are not alone. In order to post on the website and join in conversations, people need to register some basic details and agree to terms and conditions. Conversations are moderated by the Sue Ryder digital team and the community guidelines are prominent throughout the site to remind people how they should use the site. This is extremely important given the sensitive and difficult situations of many of the users of the community.

A monthly newsletter is sent to everyone who is using the community to update them on relevant news such as interesting conversations and new information that has been added to the support section.

What impact has the Online Community had?

Number of visitors June 2015 - May 2016: 24,151



Our most-read advice pages suggest what type of support people are looking for and is a potential indicator of where gaps lie in current services.

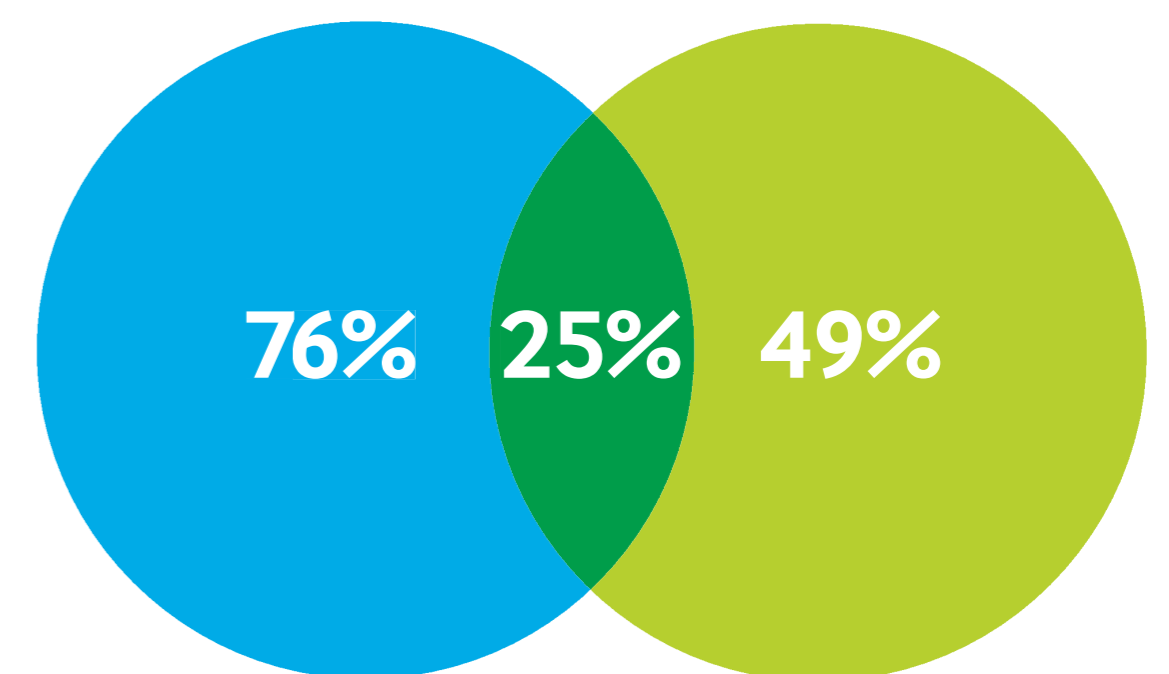
Top five advice pages:

1. What can I expect when death is near?
2. How can I cope with bereavement?
3. What can I do to help when someone is close to death?
4. What support is available for carers?
5. Can you choose where you want to die?

In May 2016, we conducted a user survey to find out who was using the Online Community and Support and what impact it was having on their lives. We received 54 responses – equivalent to about 10% of registered members.

Survey results

76% of respondents had used the Online Community section and 49% had used the information section.



Online Community

Information

Our survey showed that the large majority of our users are bereaved. However, it is worth noting that the survey asked users about their current reason for using the site, so this majority may include users who initially joined when their loved one was ill and who have continued using it after bereavement.

- 77% of respondents were bereaved
- 9% had a loved one who was dying
- 9% had a terminal diagnosis themselves

Our survey showed that the site is having a positive impact for its users.

- 75% said using the Online Community helped them feel less alone
- 80% said the information content helped them feel less alone
- 70% said using the Online Community made them feel more able to cope
- 75% said the information content answered questions that they had

“I have to say the resources are really helpful. I wish I’d found them sooner. Great website, mobile friendly and helpful forum.”

Online Community user

What next?

Sue Ryder believes that everyone who would benefit from this type of support and advice should receive it, regardless of situation, location, time of day or day of the week. We will continue to build awareness of our Online Community so that more and more people can access the support they need.

Our work in this area has also highlighted a need for Scotland’s new Health and Social Care Partnerships – which are now responsible for the provision of palliative care – to collaborate with third sector partners to provide co-ordinated emotional and practical support around the clock.

Hospice staff can promote the Sue Ryder Online Community and Support to their patients and family members using marketing materials provided by the charity.

For more information, or to request a marketing pack, please contact: Freya Willetts, Marketing Manager (Health and Social Care)

Call: 020 7554 5954
Email: freya.willetts@queryder.org

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