DIGITAL SUPPORT

WE ARE MACMILLAN. CANCER SUPPORT

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How digital services can help you and those you support

This issue of Sharing Good Practice highlights ways in which digital services – including online information, interactive tools and social media platforms – can help people affected by cancer. Signposting people to these services can be part of the support you offer. This issue also examines how health and social care professionals can benefit from having an online presence.

Our key evidence section will equip you with statistics to support decision-making or budget considerations around using technology, or investing time and effort into digital signposting.

Finally, two case studies show how Macmillan professionals are actively engaged with getting the best out of digital channels.

Would you like to join a panel of health and social care professionals who feed back to Macmillan on digital innovations that affect you? If so, please register your interest with Denise Etherington by emailing detherington@macmillan.org.uk Your opinions will help us to shape our products to better serve you and the people you support.

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What the future holds
My mother was a social worker for more than 25 years, and worked her socks off throughout. I would often hear her voice drifting up from her makeshift office in the living room long after I’d gone to bed. She’d be dictating reports into her miniature Dictaphone. To my nine-year-old self it seemed like an awfully fancy, magic contraption. But she would also cart around huge files every day in a selection of shoulder bags, endlessly lugging them in and out of the car. (As a result, my sisters and I would be able to spot a social worker a mile off, weighed down by a selection of heaving shoulder bags, brimming with photocopies and reports they’d carry around.)

Mum’s now retired, but had the resources she needed to do her job been available to her online it may have saved both her shoulders, and the vast amount of time spent photocopying forms and booklets for her clients.

As a Macmillan professional, you know there are now, thankfully, a multitude of online tools and websites available to help both you and your patients at different times after a cancer diagnosis. But with many different options available, how do you know which particular tools could benefit those you support most at different points, and have the right impact? This issue of Sharing Good Practice will give you some useful pointers.

How online tools help to reduce costs
As a vital source of support for people affected by cancer, you highlight which types of information and assistance Macmillan can provide to them. Each person will have a different set of preferences for how they digest information about cancer – some will prefer to read booklets in their own time, others will immediately go online searching for answers – and, with your guidance, will hopefully go straight to the Macmillan website in search of support.

It’s easy to assume online uptake falls into two categories – the younger know what they’re doing online and older people struggle. While this can be true, it’s not always the case. So we’re not advocating a one-size-fits-all approach, but rather to be aware of the online resources that can help those affected by cancer. An added upshot of this is that, by using digital resources instead of printed ones, we can all save Macmillan money.

‘There are now, thankfully, a multitude of online tools to help you and your patients.’
Digital support

For example, each copy of The Cancer Guide booklet costs Macmillan 52p to produce. While you don’t want to hold back providing our supporting information, sometimes you don’t need to use printed information to help. Someone could be just as happy reading the information online.

Sharing information options
Many of those you support may wish to share the information they are accessing online. There are the usual various share options available on our online spaces (the social media icons you’ll see at the top of most of our webpages) – this doesn’t have to be a publicly viewable share, either, as users can send it using a private message on Facebook, for example, or bookmark a direct link to the information.

If those you support are concerned about their children seeing cancer-related terms appearing in search, for example, if they haven’t yet shared their cancer diagnosis, then you can also highlight the option of going ‘incognito’ when browsing online. To find out how to go ‘incognito’ on different browsers, search for ‘how to go incognito’ and various instructions for different browsers will be available in the search results.

How be.Macmillan helps people affected by cancer to fundraise for us
People you support or their relatives or friends may be showing signs of wanting to give something back to Macmillan, be it volunteering, doing a fundraising challenge, or joining a focus group. If so, please direct them towards our website so we can harness their enthusiasm for the benefit of others affected by cancer.

As our ‘warehouse’ website, be.Macmillan.org.uk also provides helpful guidance and tools for fundraising, so people can use our brand for their activities and order merchandise for their events. It’s also where both you and also people affected by cancer can order all our cancer information booklets, should print format be required.
The next few pages highlight examples of the various online help you could signpost people you support to at different times in their cancer journey. You can adapt this timeline for different situations – there are plenty of additional and alternative options for different cancer diagnoses or experiences.

Next to each suggested website or online tool, we’ve set up a range of short weblinks so that you can type the address straight into your browser and access or download the information.
Digital support

At diagnosis

When someone has been diagnosed, you could suggest they may like to join the Online Community (macmillan.org.uk/community), specifically groups related to their cancer type or situation. Our Online Community is one of the foundations of our digital services. It provides a 24/7 source of anonymous emotional support, connection to others who’ve gone through the same experiences, and practical information. The Community has more than 100,000 members now, so users are likely to be able to connect with others who’ve gone through the same experiences, and find practical information, too. It was redesigned in 2015 and now provides easier navigation and quicker routes to favourite groups, and performs brilliantly on mobile devices.

One of its popular newer features is ‘Ask the expert’, in which people affected by cancer can post a question to ‘Ask a nurse’ or ‘Ask a benefits advisor’, and have an answer posted within 24 hours. Teams of professionals like you field the questions. From January to April this year, 682 questions were posted and answered, and 21,258 people viewed the answers.

Show the person you support a video
We have a broad range of videos for different cancer types and audiences, including case studies, animations, and British Sign Language videos. These include personal stories from people living with different cancer types and videos featuring professionals.
macmillan.org.uk/cancerinformationvideos

Do they have children they need to speak to about their diagnosis?
Our online ‘Talking to children about cancer’ information may help.
macmillan.org.uk/talkingtochildren

Money and cancer information
People living with cancer and their carers may have immediate money worries. Our online section walks visitors to the section through the different grants and financial assistance that may be available to them. macmillan.org.uk/moneyworries
As a professional, you can refer people to the financial guidance service through an online form and checklist at:
macmillan.org.uk/financialchecklist

Compare hospitals
My Cancer Treatment is a website built and managed in partnership between Macmillan and NHS England. Using data from the National Peer Review Programme, it gives people living with cancer information on how their local hospital’s cancer care team compares with all other teams in England, and how they’ve performed against national averages on a range of measures.
mycancertreatment.nhs.uk

The electronic Holistic Needs Assessment (eHNA)
is transforming care teams’ ability to identify all the concerns and potential support needs of people who’ve been diagnosed, and create a care plan designed to meet those needs when they appear.
macmillan.org.uk/ehna
During treatment

You can point the relatives and friends of people you support towards The Source (source.macmillan.org.uk) – a place for people to search for or share tips so they can be there for someone they know with cancer. The Source is a collection of simple, practical tips posted to the site by people who’ve been affected by cancer. The strategy behind it is to connect with people who haven't experienced Macmillan in any way but who have friends living with cancer, giving them tips for reaching out to those people living with cancer.

The tips have translated extremely well to social media. Posted tips on Facebook and Twitter had 9.3 million views in 2015, with more than 235,000 engagements.

- **Fatigue diary download**
  Cancer-related fatigue usually gets better after treatment finishes but, for some people, it continues for months or years. People may find it helpful to keep this fatigue diary, to help explain to doctors about how it affects their life. Each day, users put a cross in the box that relates to their energy level on a scale of one to six.
  [macmillan.org.uk/fatiguediary](macmillan.org.uk/fatiguediary)

- **Pain diary download**
  People may find it helpful to keep this pain diary, to help explain to doctors about how it affects their life.
  [macmillan.org.uk/paindiary](macmillan.org.uk/paindiary)

- **My Organiser**
  Is a super-helpful app that gives people living with cancer an easy way to keep track of things such as symptoms, food intake, appointments, medication (with reminder settings) and appointments. It also allows them to store important contacts and get in touch with Macmillan for more support. It’s a free download on the Android and Apple app stores, and was downloaded 6,708 times in 2015, with more than 177,000 page views.
  [macmillan.org.uk/myorganiser](macmillan.org.uk/myorganiser)

- **Is your patient part of the LGBT community?**
  If you feel unsure or embarrassed about what to say without fear of causing offence, we have practical guidance for professionals on supporting lesbian, gay, bisexual and trans people with cancer.
  [macmillan.org.uk/LGBTadvice](macmillan.org.uk/LGBTadvice)

- **Breathlessness**
  Information to help people manage breathlessness.
  [macmillan.org.uk/breathlessness](macmillan.org.uk/breathlessness)
Digital support

Living with cancer

Our interactive Financial Support Tool includes a benefits checker and an inheritance tax calculator, alongside videos and information about personal finance issues such as mortgages, savings, wills, insurance and budgeting. In the six months covering quarter four of 2015 and quarter one of 2016, the Financial Support Tool had 4,539 people visit 8,274 times, with 27,963 pageviews. The number of pages per visit is 3.38 – a high stat.

finance.macmillan.org.uk

Emotional effects
Information about coping with the emotional effects of cancer.
macmillan.org.uk/emotionalsupport

Our information in other languages and formats can help people with different needs and preferences, including British Sign Language videos, braille, large print and easy read booklets.
macmillan.org.uk/otherformats

After cancer treatment downloadable guides
There is one guide for your patients – macmillan.org.uk/aftertreatmenttoptips – and one for you as a professional: macmillan.org.uk/hscpsaftertreatment

Challenge events
The person you support, or their relatives and friends, may feel compelled to fundraise for Macmillan.
macmillan.org.uk/challengeevents

Local support
Did you know that our In your area section brings Macmillan to people where they live by aggregating five sets of data? Users can easily filter the data to find benefits advisors, Macmillan information centres, self-help and support groups, fundraising events and volunteering opportunities near them.
macmillan.org.uk/inyourarea

At the end of life

Advanced cancer information
Our online information looks at ways to cope with symptoms, side effects and the emotional impact of advanced cancer.
macmillan.org.uk/advancedcancer

Caring for someone with advanced cancer video
Former Macmillan CEO Ciarán Devane talks about his experiences as a carer.
macmillan.org.uk/caringforsomeone

Moving forward
Our online information for grieving relatives and friends can help people cope with bereavement, provides information and practical advice and, when they are ready, offer ways to celebrate the life of their loved one.
macmillan.org.uk/bereavement
Key evidence

This section presents some key data around internet use. It also examines how professionals signpost those they support to online information, using financial support as an example, and suggests how barriers to signposting might be overcome.

General online access and usage
Data\(^1\) from the Office for National Statistics (ONS) shows that in Great Britain in 2015:

- \(86\%\) of households had internet access (up from 57\% in 2006)
- \(78\%\) of adults in Great Britain accessed the internet every day (up from 35\% in 2006)
- \(61\%\) of adults used social networking sites

Age
ONS data\(^1\) suggests that at the start of 2015 (January to March) the internet had been used recently by:
- \(99\%\) of adults aged 16 to 24
- \(71\%\) of adults aged 64 to 74
- \(33\%\) of adults aged 75 or above

Age UK says it believes that ‘older people should be encouraged and supported to access the internet, but that those who do not want to should continue to be able to access services and support that suits them.’\(^2\)

Some older users may find tablets more intuitive and user-friendly than desktop or laptop computers.\(^3\) Research from Ofcom suggests that rising use of tablet computers is driving an increase in the number of older people going online.\(^4\)

Despite barriers to accessing the internet for some older people, evidence suggests those who do go online see benefits from doing so. The Pew Research Centre in America found that 79\% of adults aged 65 or above who used the internet agreed with the statement that ‘people without internet access are at a real disadvantage because of all the information they might be missing,’ while 94\% agreed with the statement that ‘the internet makes it much easier to find information today than in the past.’\(^5\)

Levels of signposting among health and social care professionals
Macmillan has a wealth of reviewed, accredited and user-friendly information on understanding, diagnosing, treating and coping with all cancer types. Alongside this, we provide a wide range of information, online and in booklet form, about organising and managing the practicalities of going through cancer – from money worries to working issues to travel and more.

A key to helping people affected by cancer get the most from this information is signposting them to it as a start.
Key evidence

Research conducted by GfK on behalf of Macmillan draws conclusions on the level of signposting by health and social care professionals. While the majority (90%) of professionals surveyed claim to signpost people affected by cancer, the frequency is low.

Over half of health and social care professionals signpost less than once a week.

Case study: signposting to online financial information

We asked Chris Jones, a Macmillan welfare rights adviser, why he thought professionals tend not to signpost people in their care to online financial support in particular:

‘I don’t think people are aware of the full range of online financial support available. There might be an assumption that important information like this has to be provided in person but actually online financial support can really empower people and allow them to make informed choices about their financial situation.’

If we take a closer look at signposting specifically to Macmillan resources we find 8 in 10 professionals recommend Macmillan’s website and two-thirds signpost to other Macmillan services, such as the support line. The research found that while our website is highly referred to, services that are more specific are less used, as they tend to be less well known.

Specialist cancer nurses carry out signposting most frequently (2.4 times a week). GPs and other generalist roles tend to signpost the least often (GPs, 0.7 times a week). This is likely due to time pressures and high patient caseload meaning less time spent with each patient. Specialist cancer roles, however, spend more time on average with patients and have a broader knowledge of the specific support and information available.

Barriers to signposting

When we asked professionals what they see as the barriers to signposting patients to additional information and support, the main reason was that:

82% felt that ‘someone else is better placed to offer this information’.

A majority of professionals (62%) feel financial information is best offered by someone else, which could indicate a lack of understanding or knowledge of the financial support available to people affected by cancer. Macmillan is in a good position to place itself as a comprehensive and authoritative source of financial information and support. That said, professionals in a Macmillan post are already more inclined to refer patients towards our financial support than to other charities.

There is often a stigma around accessing benefits and support which can be seen as a barrier to signposting patients. It’s not something that generally comes up in a consultation with a GP or oncologist which is why specialist cancer nurses are often the first to address financial worries. Which underscores the value of a tool such as the electronic Holistic Needs Assessment (eHNA): an iPad or tablet survey tool that allows professionals to capture the range of concerns patients have, early in their cancer journey, so that a holistic care plan can be created and specific worries such as money can be anticipated and information support provided. As part of the Recovery Package eHNAs are carried out with patients at various points through their cancer journey. This assessment aims to address a person’s key issues and concerns at that time. It is often at this point financial worries are highlighted to the nurse or key worker who can then signpost to support.

The type of support depends on each individual but often a combination of online and in-person information is best.
Combining digital and other support
There are many different challenges to people accessing online support, specifically financial support. These vary from little knowledge of the information available, to lacking the IT skills or equipment to access the support. Although 5.4 million people accessed our online information and support in 2015 (an 8% increase on 2014), there is still more we can do to ensure people get the right mix of support at the right times.

Chris Jones says: ‘Some people may not feel confident about following online information or advice and may want to run through things with a benefit adviser or financial guide for example.

‘Our support line can then complement the online information and people can email us asking for a call back to discuss further.’

This combination of online support and the availability of an actual person to contact about concerns and worries is a strong approach. We know around 66% of professionals have recommended the Macmillan Support Line to patients. Through the support line people can speak to our benefits and welfare advisers who are able to supplement and signpost to our online resources.

Chris says: ‘The comprehensive instant information available online should definitely be encouraged. Some people may feel more comfortable with accessing online financial support rather than calling someone and discussing personal details, and this can be encouraged by professionals by signposting them to appropriate online channels.’
Case studies

Two Macmillan professionals explain how they use digital channels to both support people affected by cancer, and for professional development.

Debbie Provan
National Allied Health Professional (AHP) Lead for Cancer Rehabilitation and Macmillan TCAT Project Manager

How do you think signposting people affected by cancer to digital channels can help them?
It’s another information source that’s quick and easy, and in theory should be up to date. It really increases the readiness and availability of information for patients.

How do you and your colleagues let people affected by cancer know what’s available?
At the moment I’m involved in one of the TCAT (Transforming Care After Treatment) projects in Scotland. The aim is to embed the holistic needs assessment within care planning into the pathway, to empower people and promote self-management. We have developed a Supportive Care Directory, which is a list of places people can go for support and information, whatever issue they raise through the holistic needs assessment. Most of the resources are online but we also have Macmillan booklets and the Macmillan Support Line number in the Directory.

A couple of years ago Macmillan gave us some funding to integrate the work we had been doing locally with Ayrshire Cancer Support and the local Macmillan Cancer Information Support Service. Together they formed a website called Ayrshire Cancer Network. This is a platform which signposts local support groups and other sources of information and support for people with a cancer diagnosis.

Does social media have a role to play?
We tend to signpost patients to websites mostly, but indirectly people might end up on social media. If they use the Macmillan website, for example, it’s got the support community on there and they also advertise things like Twitter chats and Facebook groups.

Locally my experience is that health boards tend to be quite strict on regulation, in terms of what information we put on social media. So we might promote things through our communications department who have a Twitter account and a Facebook account, rather than having our own accounts for local services.

Professionally I use social media a lot, but I think it’s important to emphasise the importance of people keeping themselves right from a professional point of view.
That could be through getting advice about social media from their professional body or from their local communications department. But people certainly shouldn’t be put off, because I definitely think there are more pros than cons to using social media.

**Are there any success stories you’ve seen, where a patient has found a digital source of information particularly helpful?**

Through my national role (which is part Macmillan funded and part Scottish Government funded) I spoke to a cancer physiotherapist in Dundee who had a patient come to her through a website they had seen promoted on Twitter. That individual had been really struggling to find information and support, but thanks to digital signposting they found what they needed, and ended up seeing a specialist cancer physiotherapist.

**How useful do you find digital channels for connecting with other professionals?**

They’re hugely beneficial. I use them all the time, particularly within my national role. I use Twitter, and there are some good conversations happening on LinkedIn, so I use this a bit more from a dietetic point of view. I’ve managed to reach out and find out a lot about different services that are out there.

Through my national role I also facilitate a blog called AHP Scot Blog, a professional blog for AHPs in Scotland supported by the Chief Health Professions Officer. It’s a really good way of showcasing work to a wide audience. Without such a forum individual AHPs would never be able to reach that audience so quickly and easily, so it’s a great way of reaching out and making connections.

There are lots of people I’ve had conversations with and collaborated with as a result of social media connections, despite never having met them in real life, so it’s been really beneficial for me.

**Are there any professional successes you’ve had as a result of digital communication?**

My connection with Mandy Trickett (see overleaf) came about through Twitter. We’ve formed a good professional relationship, and I became her mentor while she was going through a fellowship programme focusing on developing cancer rehabilitation within her local hospice. We’ve been able to collaborate on quite a few things since then.

I also organised an event earlier this year, funded by Macmillan, to bring AHPs working in cancer and cancer rehab services across Scotland together. The event was largely advertised through social media. Some people came along because they had heard about it through Twitter, and they then joined the community of practice. Again, that kind of communication enables us to exchange more information, update current practice and share resources.
Mandy Trickett
Macmillan Specialist Physiotherapist

How do you think signposting people affected by cancer to digital channels can help them?
I think it promotes autonomy, self-management and behaviour change, moving away from a paternal approach and encouraging patient participation. There’s more information available digitally than we could ever provide through leaflets, so directing patients to live sites is often better. If you work in a regional centre, directing patients to websites or other digital media can make it easier to keep people up to date with what’s happening in different areas. More and more patients of all ages are also choosing to use mobile apps to monitor physical activity levels, rather than paper diaries.

How do you and your colleagues let people know what’s available?
We have lots of leaflets and resources from Macmillan, and in those are websites we can direct patients to for additional support or specific information. We might also direct patients to local groups such as those within local authorities we work in partnership with.

If people can’t look online themselves they may ask a relative, friend or neighbour to help, or go to their local library. I never assume that because someone’s elderly they’re not interested in social media or digital communication.

Does social media have a role to play?
I use social media to network with other healthcare professionals but I always make sure to disassociate myself from my employer. That’s very important. On Twitter most people say ‘views are my own’ to make this distinction.

If we are working on a project within NHS Tayside we go through our communications department to share our work on social media. If you’re using social media professionally, it’s important to follow the guidance your employer gives you otherwise it can be difficult.

Some hospices in Scotland have their own Facebook and Twitter pages. It’s done very sensitively and tastefully and I think it’s really powerful. It unites people in a way you couldn’t do before.

How useful do you find digital channels for connecting with other professionals?
I use Twitter a lot, professionally. I’m the Scottish Representative for the Association of Chartered Physiotherapists in Oncology and Palliative Care, and I use Twitter to disseminate information. I have made contact with physiotherapists all over the world. Twitter is also great for conferences – I can use event hashtags to tell people what’s happening and if I can’t attend I can still follow what’s happening by following the hashtags.

On Facebook I’m part of two groups. Palliative Rehabilitation, set up by Gail Eva and Cathy Payne, is a supportive place where physios, occupational therapists and other health care professionals worldwide can post articles, ask questions and share information. The second group, Palliative Re-enablement, is made up of people looking at the service they provide and asking questions about their rehabilitative focus. I’ve been able to make really good contacts with people through social media, while always ensuring...
I follow my employer’s guidance.

I also use the Community of Practice set up by Debbie Provan, National AHP Lead for Cancer Rehabilitation, on the Knowledge Network, Scotland. It’s a group where AHPs interested in cancer rehabilitation can share articles and details of current research. And there’s the AHP Scot Blog, which has generated interesting discussions through the sharing of views and project work.

Sharing digitally speeds things up for everyone. It means we’re not all trying to reinvent the wheel – we can pick up where others have left off and take things forward.

Are there any professional successes you’ve had as a result of digital communication?

I worked on a project in 2012 which got a lot of digital coverage when we first presented the results. It was on the AHP Scot Blog, and NHS Tayside put it on their Facebook page. I had connected with Debbie Provan through Twitter previously and she became my mentor for the project. We won a PAHA (Physical Activity and Health Alliance) Award in 2014 and the project was also featured in Mac Voice. In the past a project from several years ago would be old news by now but in May this year I was still presenting the findings of the project at a national conference. As it’s still out there on digital channels, people come across it and ask us to share. That’s why it’s so important to maintain professional standards when using social media.

I’ve made connections all over the world with people involved in palliative care rehabilitation and cancer care. Recently someone in England posted in the Palliative Rehabilitation Facebook group with questions about risk associated with exercise and bony metastases. Very quickly people answered with current guidelines, details of what the ACPOPC (Association of Chartered Physios in Oncology and Palliative Care) are doing and examples of their own practice. Things like that are really helpful.

I think digital communication encourages people to ask questions and find answers. It’s an open and welcoming way of finding information and members are willing to share their expertise with others who want to learn.

I’d be lost without social media, professionally. It’s a great way to network, keep up to date and connect with specialists across the world. And if you are a specialist, it’s a great way to share your knowledge, in line with your professional body and employer’s guidelines.
Further reading

Health and Care Professions Council (HCPC). Use of social networking sites
Guidance from the body that regulates allied health professionals.
hpc-uk.org/registrants/standards/socialnetworking

A report on how digital technology can transform healthcare.
nuffieldtrust.org.uk/node/4548

Nursing and Midwifery Council. Guidance on using social media responsibly
Information for nurses on social media good practice.
nmc.org.uk/standards/guidance/social-media-guidance

Royal College of GPs. Social Media Highway Code
A guide for GPs and other healthcare professionals who want to make the most out of social media, while meeting professional obligations.
rcgp.org.uk/social-media

Sharing Good Practice, Spring 2013.
Macmillan’s Social Media team discuss how social media can allow prompt communication between colleagues, and between people affected by cancer. Download this issue at macmillan.org.uk/sharinggoodpractice

The Tinder Foundation is a charity which supports digitally and socially excluded people to improve their lives through digital. This report looks at the crossover between people who are digitally excluded and those at risk of poor health.
tinderfoundation.org

Introduction to social media: Macmillan Learn Zone course
This resource will help you to use information technology tools professionally and efficiently.
learnzone.org.uk/socialmedia

References

References for ‘Key evidence’ (pages ix–xi)


6 GfK on behalf of Macmillan Cancer Support. Health and Social Care Professionals Research: Summary findings from the quantitative research phase.

References for ‘Case studies’ (pages xii–xv)