Mac Voice
For Macmillan Professionals | Issue 89 | Summer 2019

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In focus
Men’s health

Sharing good practice
Social care
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Writers wanted
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Welcome
Welcome to the Summer 2019 edition of Mac Voice.

On the cover of this issue is Craig Menzies, Macmillan Programme Manager for Macmillan @ Glasgow Life. He explains how this library-based service has grown to provide information and support to more than 15,000 people affected by cancer, and emphasises the vital contribution of volunteers (page 8).

You can read how Macmillan is working with insurance company Aviva to help speed up insurance claims for people with cancer on page 14. And on page 16, we find out how a new programme in Harrogate is encouraging discussion on choices for end of life care.

Our In focus section is all about men’s health, from prostate screening clinics in local football clubs, to health education for men in prison and a new Look Good Feel Better programme for men.

Sharing good practice looks at the important impact of social care – including Macmillan’s work to support statutory services to better meet people’s social care needs. We also highlight key learnings from social workers supporting people with cancer at the end of life.

Thank you so much to all the Macmillan professionals who kindly gave us their feedback as part of our recent communications survey. We reveal the results – and the winners of our fantastic prizes – on page 4.

Rachel Hunter
Managing Editor
News
4-7  The results of the Macmillan professionals communications survey, a new video for people with poor appetites and a scheme to provide pamper packs for people having chemotherapy

Features
10-11  A catering event for people with head and neck cancer
12-13  Community cancer care in Buckinghamshire
14-15  Our work with insurance company Aviva
16-17  Encouraging patients and carers to think ahead
18-19  Speech and language therapy in palliative care
20   Identifying services to support health and wellbeing

Sharing good practice pull-out
Social care
In focus: Men’s health
22-27  Three professionals explain how they are supporting men affected by cancer and raising awareness of men’s health issues

Resources
28  New and updated information from Macmillan
Mac Voice survey results

Thank you to everyone who completed our survey about Mac Voice and other communications for Macmillan professionals.

We had more than 550 responses, representing around 6% of the Macmillan professionals workforce. We heard from people working in a wide range of roles, including nurses, information and support professionals, allied health professionals, benefits advisers, counsellors, GPs and support workers. We have illustrated some of the findings below.

Your responses have provided valuable insight into how you use Mac Voice and the sections you find the most useful. We will be thinking about how we can improve our content, and how we can make sure that more professionals can access Mac Voice in the way that works best for them.

If you would like to share your thoughts about Mac Voice, or to submit an article or idea, please email us at macvoice@macmillan.org.uk

Congratulations to Michelle Bull, Macmillan Integrated Cancer Care Team Project Lead, who won a Boots No.7 hamper, and Abigail Pudner, Macmillan Benefits Support Worker, who won a £50 M&S voucher.

52% read every issue.
44% read some issues.
16% read Mac Voice online.
86% say Mac Voice has a positive impact on the service they provide to people affected by cancer.
New video on managing poor appetite

A new online resource is available to support people with cancer to manage poor appetites.

Malnutrition and loss of muscle mass are extremely common in people undergoing treatment for cancer. The incidence varies depending on tumour type, stage, treatment, and the degree of symptoms and side effects. Poor appetite and subsequent weight loss can lead to delays in treatment, as well as increased morbidity and mortality.

Many people living with cancer, and their friends and families, turn to the internet for help during treatment. A recent Google search for ‘diet and cancer’ yielded 652 million hits, many of which are unregulated websites giving people contradictory advice and false hope.

Due to the increasing numbers of people diagnosed with cancer in the UK, it is almost impossible for everyone to have evidenced-based, one-to-one advice from a registered oncology dietitian. This is usually reserved for patients requiring support for tube feeds, swallowing difficulties, pancreatic enzyme replacement therapy, stoma advice or dietary management for bowel obstruction.

However, questions about diet are often among the first questions that patients have, and other health care professionals are in a position to provide top-line information.

In order to reach more patients, and provide extra help for healthcare professionals, oncology dietitians at the St Luke’s Cancer Centre (part of the Royal Surrey County Hospital in Guildford) have developed a new online resource.

With sponsorship from Macmillan and help from the hospital graphics department, they have written and produced an animated video called What to do if you lose your appetite during cancer treatment. This is available at www.royalsurrey.nhs.uk/st-lukes/nutrition-and-dietetics and on YouTube at www.youtube.com/watch?v=N-70ISXF8y4

It provides detailed information and encouragement on managing poor appetite, with tips for food fortification and high energy recipe ideas, in line with the European Society for Clinical Nutrition and Metabolism’s Guidelines on Nutrition and Cancer. We hope that this will be a valuable resource for anyone wanting to find evidence-based advice on managing their diet during treatment.

In brief

Breast screening programme review
A review of England’s breast screening programme commissioned last year has now published its findings. The review was co-chaired by Macmillan Chief Executive Lynda Thomas and calls for a ‘re-set’ of the breast screening programme. The full report and recommendations are available at gov.uk/government/publications/independent-breast-screening-review-report

New Chairman appointed
On 1 May 2019 Richard Murley started in post as Chairman of Macmillan’s Board of Trustees. Richard replaced Julia Palca, who worked relentlessly to champion the needs of people living with cancer during her nine years in the position, as well as the role of volunteering. Julia stepped down to take the role of Chair of City University of London. Richard has extensive experience across the finance, charity, legal and healthcare sectors and was already a Macmillan Trustee. You can find out more about Macmillan’s Trustees at macmillan.org.uk/about-us

Newly branded covers
Macmillan has started to roll out new covers for patient information booklets and leaflets in line with the refreshed brand launched last year. The new covers are based on the findings of a survey sent to both health professionals and people living with and affected by cancer. We aim to ensure that the photos used are as relevant as possible to the topic covered in the information. The titles on the covers now appear in orange, teal, blue, pink, and purple, as well as the recognisable Macmillan green. If you spot the new covers and would like to give us your feedback, please contact Emma Welland at ewelland@macmillan.org.uk
Macmillan outreach work raises awareness of skin cancer

An update from Macmillan Skin Cancer Care Coordinator Michelle Forsyth.

Skin cancer is preventable and often treatable, but early detection remains paramount.

I am a Macmillan Skin Cancer Care Coordinator at Blackpool Teaching Hospitals NHS Foundation Trust. My role is to provide support to clinical nurse specialists, patients and carers.

The rising incidence of skin cancers on the Fylde Coast led the skin cancer team to seek opportunities to work differently to raise awareness of skin cancer and the importance of sun protection. We have developed outreach work and educational sessions in collaboration with the Karen Clifford skin cancer charity ‘Skcin’. This has been a significant learning curve, and we have shared more information about this work in the Winter 2017 edition of Mac Voice.

Following initial support by Macmillan, my post is now permanent within the service. The role has allowed us to reach thousands of people by visiting places in the local community such as primary schools, nurseries, colleges, hair, health and beauty Professionals, outdoor workers and local councils.

The case of a council worker called Barry illustrates the impact of skin cancer awareness training. One of Barry’s colleagues attended a presentation I gave at Blackpool Council. Barry then asked for advice from this colleague, who said that it looked as though he should get his mole checked. This led to Barry being diagnosed with a melanoma and getting timely treatment. He has since recovered well.

The trust is now seeing people attend fast-track appointments for worrisome lesions, after attending an educational session in the community. This outreach work has been described as ‘invaluable to the skin cancer team’.

The trust is currently implementing support worker roles across various specialties.

Jackie Brunton, Lead Cancer Nurse, values the contribution of cancer support workers to a clinical setting. She says, ‘Those services developing support worker roles are seeing a huge impact for patients, their loved ones and the teams they are supporting. One size does not fit all, and roles are adapted to meet the individual service and team needs.’

What’s coming up?

July
Ethnic Minority Cancer Awareness Month
vincerequality.co.uk

Sarcoma Awareness Month
sarcoma.org.uk

Health Information Week
1-7 July
kfh.libraryservices.nhs.uk/patient-and-public-information/health-information-week

August
Douglas Macmillan’s birthday
10 August
macmillan.org.uk/about-us/who-we-are/organisation-history.html

September
Blood Cancer Awareness Month
bloodwise.org.uk

Childhood Cancer Awareness Month
childrenwithcancer.org.uk

National Lymphoma Awareness Week
9-15 September
lymphoma-action.org.uk

Head and Neck Cancer Awareness Week
16-20 September
makesensecampaign.eu

World’s Biggest Coffee Morning
27 September
coffee.macmillan.org.uk

Further information

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Pampering patients in the Tameside Macmillan Unit


Mossley Cancer Committee, which raises money for local cancer charities in Tameside and Glossop, has launched a new scheme to put together pamper bags for people beginning chemotherapy at the Tameside Macmillan Unit.

The bags contain a variety of useful items, which can include:

- toiletries, such as body spray, hand cream, soap or mouthwash
- self-care items, such as a nail file, tissues or wet wipes
- items to help keep occupied, such as puzzle books, pens and a notepad
- small items of clothing to stay warm, such as a hat, a head scarf, gloves or socks
- light refreshments, such as a bottle of water, sweets or biscuits
- items to promote relaxation, such as an eye mask for sleeping or a lavender bag.

The idea for the scheme started in 2016, when social worker Amy Longson wanted to do something for people affected by cancer. Rather than signing up for a traditional sponsored event, she explains, ‘I just thought it would be nice to try and collect things to help people starting chemotherapy treatment.’

Amy made a request on social media for local individuals and companies to offer items at reduced rates. She received a great response.

Mossley Cancer Committee was inspired by Amy’s idea and wanted to continue offering the chemotherapy pamper bags for people at the Tameside Macmillan Unit. The committee celebrates its 50th birthday next year and has supported the Tameside Macmillan Unit in many ways.

When people go to hospital for their first chemotherapy session, it can be a daunting experience. Some may not know what items they will need. Members of the Mossley Cancer Committee thought carefully about this issue and made a list of what might be useful.

The committee buys the items from local shops and businesses, and are always open to new ideas for their list. So far, they have given out about 200 pamper bags and intend to carry on the scheme for many years to come.

People visiting the Tameside Macmillan Unit have been very appreciative. One patient said, ‘I was touched and grateful that somebody cares enough to make such a generous gift’. Another patient explained that, when going through cancer treatment, ‘it is the little gifts and gestures that make all the difference’.

To find out more about the scheme, visit tamesidemacmillan.co.uk/pamper-bags.
What is Macmillan @ Glasgow Libraries?
The Macmillan @ Glasgow Libraries Programme approaches access to cancer information and support in a unique, ambitious and innovative way. This partnership between Glasgow Life and Macmillan was launched in 2012, and now ensures that people affected by cancer in Glasgow are no more than one mile from cancer information and support provision. Based within local libraries, our 97 volunteers provide a listening ear, information and signposting to a huge range of local and national services. Through our partnership with Cancer Support Scotland, we also deliver counselling and complementary therapies.

Q&A: Craig Menzies

Job title
Macmillan Programme Manager

Location
The Mitchell Library, Glasgow

In post
Since 2012

Contact
Craig.Menzies@glasgowlife.org.uk
At inception, we challenged ourselves to create a service that is accessible, quality assured and relevant to anyone affected by cancer, including families, friends and carers. And importantly, we wanted to ensure that our volunteers are at the heart of everything we do. Fast forward to today, and our programme has had more than 15,500 attendances, and almost 50% of those have been family members, friends and carers. We believe this statistic shows the need for an alternative to clinical-based support systems, to allow improved access to support for anyone affected by cancer, not just the patient.

What does your role involve?
I have been with the programme since it was launched in 2012. I joined as a service delivery manager, and then took over as programme manager in January 2016. I am responsible for managing our partnership approach to the development, delivery and sustainability of the service. My day-to-day work varies significantly, but focuses on integrating our programme into the wider cancer environment in Glasgow. We aim to ensure that every individual affected by cancer has access to the wide range of services available.

What are the main challenges?
Like any innovative programme, we have experienced challenges in changing the way people think about service delivery. The option of a non-clinical, community-based and volunteer-led service is very different to many existing services. It has taken time to find our place within the cancer pathway, which has historically been based across clinical settings. However, we have made significant progress over the past couple of years, with a growing appreciation of the role of non-clinical services, for patients and also families, friends and carers.

And what about the rewards?
It sounds like a cliché, but my whole role is really rewarding in many ways. Every day we hear of the impact that our services are having on people, whether that is someone who has recently been diagnosed, or someone who has lost a loved one to cancer. It is always rewarding for the staff team to hear that we have made a difference, and that feeling is enhanced further when we hear how fulfilling this work is for our volunteers. To date, our volunteer contribution is over 44,000 hours donated to the programme. That’s a huge number of people making their own choice to support local people affected by cancer.

We were absolutely thrilled to be awarded a Macmillan Excellence Award in 2017. We are also really proud of our 4.75 (out of 5) score for the Macmillan Quality in Information and Support Services (MQuiSS) standards. These things simply re-iterate the standard of support on offer from our incredibly dedicated volunteers and staff.

How would you like to see the service develop?
Our work with our volunteer programme, which is increasingly acknowledged as best practice, both locally and nationally, leads us into an exciting new era. In September 2018, we entered into a new funding agreement with Macmillan This will see us develop a centralised programme of Macmillan volunteering opportunities – the first of its kind in the UK. The idea is to use the existing skills, knowledge, experience and networks built by the Macmillan @ Glasgow Libraries team to support partners in developing volunteer programmes of their own. This work is already underway, through partnerships with the NHS and Glasgow City Council. Our ambition is that this will lead to a diverse, accessible and quality-assured range of Macmillan volunteering opportunities across the city.

‘Volunteers are at the heart of everything we do.’

How does being a Macmillan professional support your work?
There is an incredible amount of knowledge, experience and support available to us from the geographical team in Scotland, who are always just a phone call away. Their support, along with the Macmillan brand, has allowed us to keep on challenging historical barriers. The trust and quality assurance associated with Macmillan undoubtedly encourages our partners to work together with us to drive innovation.
A catering event for people with head and neck cancer

Macmillan Speech and Language Therapist Chloe Jarvis and Specialist Oncology Dietitian Claire Davis describe an event to boost confidence around eating and drinking.

Head and neck cancer and its treatments can have a significant impact on a person’s ability to eat, drink and enjoy mealtimes. This affects not only the person with cancer, but also their family and friends. Food tends to become a medicine, rather than being part of a pleasurable social experience.

On 9 November 2018, catering students at City College Plymouth held a special event at the college’s restaurant. This was intended to support people recovering from head and neck cancer to explore the culinary world. The event aimed to stimulate appetites and increase confidence around eating and drinking.

Working with catering students
We came up with the idea for the catering event with Clinical Nurse Specialist Steph Murgatroyd. We are based in the head and neck cancer team at University Hospitals Plymouth NHS Trust.

With the support of Macmillan and the head and neck cancer team, we visited the catering students before the event. This gave us a chance to brief them on the impact of head and neck cancer, and specific flavours that would stimulate saliva and enhance taste.

Head and neck cancer treatments often result in:

• dysphagia (difficulty or discomfort in swallowing)
• xerostomia (dry mouth) and
• dysgeusia (taste changes).
All these distressing symptoms can affect appetite and socialising. This can have a big impact on patients, with some feeling that they will never enjoy mealtimes again. We talked to the catering students about these eating problems and the need to modify textures for people with dysphagia. The students rose to the challenge and created a variety of delicious canapés, including chicken tagine with pomegranate jelly and green tea sorbet.

Another aim of the event was to create a supportive social environment. Patients who attended were encouraged to:

- try flavour combinations that they may not have considered
- talk with others who may have been experiencing the same difficulties.

It is often recommended that patients eat little and often, rather than challenging themselves with big meals. Having small canapés made this possible, without people feeling as though they were wasting food. One attendee said, ‘I haven’t had flavours like that in years.’

**Inspirational talks**

Various speakers presented throughout the day, with talks from the local Mustard Tree Macmillan Cancer Support Centre on adjusting to life after treatment and coping with fatigue.

We also heard from Ryan Riley, who founded Life Kitchen, a charity that has collaborated with River Cottage to offer free cooking classes to people living with and beyond cancer. Ryan spoke about his experience and gave tips for enriching flavour. His talk was very well received, and several people requested a local cooking demonstration in the near future.

Overall, feedback about the catering event was overwhelmingly positive and students gained invaluable experience in cooking for people with dysphagia.

Attendees particularly enjoyed meeting others in a similar situation and the opportunity for social interaction. There were also several positive comments about the tasting aspect of the day. One person said that the canapés were ‘clever, imaginative and superbly prepared’.

With ongoing support from Macmillan, we hope to run a catering event every year. This will give future head and neck cancer patients the opportunity to enjoy eating and socialising again after their treatment.

**Further information from Macmillan**

Macmillan’s booklet *Recipes for people affected by cancer* contains simple, appetising meal ideas and practical tips. It includes a range of recipes that aim to address the different eating problems that people with cancer may face. Some of the tips include:

- People who have problems swallowing should try eating softer foods. They can cut ingredients into small slices or chunks. Adding sauces or gravies may also make food easier to swallow. It may be necessary to use a liquidiser or blender for some dishes.

- People who have a sore mouth may need to avoid dry foods and add sauces or gravies. Creamy foods may be easier to eat. They should also avoid foods that are spicy, acidic or salty, such as chilli peppers, citrus fruits and tomatoes.

- People whose sense of taste has changed may want to eat foods that have stronger flavours. They can add seasoning to their cooking, but certain spices may make a sore mouth worse.

To order a free copy of Macmillan’s award-winning booklet *Recipes for people affected by cancer*, visit [be.macmillan.org.uk](http://be.macmillan.org.uk)

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**Further information**

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Cancer care closer to home

Macmillan Systemic Anti-Cancer Therapy Outreach Project Manager Amy Peterson on developments in community cancer care in Buckinghamshire.

The treatment of cancer with medicines is commonly referred to as Systemic Anti-Cancer Therapy (SACT). Buckinghamshire Healthcare NHS Trust recognises the need to ensure safe and sustainable services while meeting an increasing demand for SACT. To address this, we are working in partnership with Macmillan to develop outreach cancer clinics in community settings.

Currently, the trust’s SACT service is delivered across the two acute care sites at Stoke Mandeville Hospital in Aylesbury and Wycombe Hospital in High Wycombe. The trust piloted an outreach site at Marlow Community Hub in August 2017. Macmillan then provided £350,000 to expand the service throughout the county. Clinics at Thame Community Hub launched in early March 2019.

The trust is considering delivering some intravenous medicines, with careful attention to the risk of adverse reactions and pharmacy logistics. Both Marlow and Thame Community Hubs have bedded bays to facilitate these treatments, depending on implementation plans.

In July this year, we will open a third outreach site at Amersham Hospital. This new location will enable a greater proportion of the trust’s cancer patients to receive cancer care closer to their home.

In early February, the Macmillan SACT Outreach Team also designed an oral oncology clinic run by nurses at Stoke Mandeville Hospital. This clinic benefits about six patients every week. Many people who live in Aylesbury and the surrounding areas can now have a quieter patient experience, compared to attending the busy hospital day care unit.

People can avoid the cost of parking fees, anxiety and longer travel times.

The hubs are re-purposed community hospitals used across a variety of services including physiotherapy and general outpatients. At the community clinics, patients can receive central line care, pre-chemotherapy assessments and oral and subcutaneous (under the skin) cancer treatments. These have all been agreed as suitable for delivery within the outreach setting.

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Measuring the impact

Over 300 patient visits were recorded in the first 18 months of running the pilot scheme at Marlow Community Hub.

Ongoing monthly Key Performance Indicators measure:

- the number of patients receiving SACT locally
- the types of treatments offered
- the number of clinics scheduled
- the subsequent extra capacity in the day care units of Stoke Mandeville and Wycombe Hospitals.

Patient satisfaction will also be measured using standard surveys.
Once the outreach service is fully implemented, we expect 40 patient visits per week to be relocated to community hubs. This amounts to approximately 140 patient visits per month or 1,680 per year. As a result, we estimate that the day care units at Stoke Mandeville and Wycombe Hospitals will have extra capacity of up to 12% (based on the total number of 14,500 outpatient treatment interventions in 2017).

**Improving patient wellbeing**

Healthcare experts and current patients say that the outreach sites have a positive impact on well-being. As treatment is available closer to home, people can avoid the cost of parking fees, anxiety and longer travel times to Stoke Mandeville or Wycombe Hospital.

The first patient at the Thame Hub, who was receiving treatment for bowel cancer, said: ‘This is wonderful because I’m just down the road and it can cost me up to £9 for parking at Stoke Mandeville.’

Shelley Orton, Macmillan Partnership Manager in Buckinghamshire, explains: ‘Travelling long distances for cancer treatment can be stressful, when you should be able to focus on getting better. That’s why Macmillan has invested £350,000 to fund four staff members for two years, so they can get this project going.’

Neil Macdonald, Chief Executive at the trust, adds: ‘This partnership with Macmillan is great news for people with cancer in Buckinghamshire, who will be able to get the same expert care from our nursing teams, but in a hospital closer to their home.’

**Looking to the future**

A key aspect of the trust’s Quality Priorities is to innovate and develop services. Delivering cancer care closer to home puts this strategy into practice. The Macmillan SACT Outreach Team is currently considering:

- offering community hub staff training with Macmillan resources
- signposting and/or offering patients support services, such as dietetics or physiotherapy.

The community hubs may also host local health and well-being events in future. So, watch this space for further developments in community cancer care in Buckinghamshire.

With thanks to Matron Penny Boon (now retired), Consultant Nurse Annie Richards, Advanced Nurse Practitioner Asha Mathew, Macmillan SACT Outreach CNS/Team Leader Francesca Lis and Macmillan SACT Outreach Chemotherapy Nurse Dina Nogueria.

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**Further information**

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macmillan.org.uk/macvoice
Helping to speed up insurance claims for people with cancer

Macmillan is working with insurance company Aviva and cancer nurse specialists to support quicker decisions on insurance claims for people with cancer.

A cancer diagnosis can be sudden and unexpected. It can affect every area of a person’s life, including their finances. Research by Macmillan shows that 83% of people experience a financial impact from cancer, and these people are, on average, £570 a month worse off.

This is usually caused by a combination of reduced income, as people may have to stop working during treatment, and additional costs. These include costs associated with regular trips to medical appointments or increased energy bills.

Many people have insurance in place to protect them from the financial impact of cancer. Protection insurance policies like critical illness cover can pay out a single lump sum if a person is diagnosed with a serious illness, such as cancer.

However, the time it takes for a critical illness claim to be processed can exacerbate the financial impact of a cancer diagnosis and cause unnecessary worry for people. The processing time for a critical illness claim varies across the sector, but 60 days is not uncommon.

Most of this time is taken up by the insurer waiting to receive the necessary medical evidence from the patient’s consultant. By exploring other ways of providing this evidence, claim times could be reduced significantly.

Macmillan is working with the insurance company Aviva and cancer nurse specialists (CNS) to address this problem. The partnership started with a six-month pilot in 2014, which aimed to test new methods of providing medical evidence to insurers through a CNS, rather than the patient’s consultant.

Specialist nurses who participated in the pilot indicated that their main motivation was to help patients manage the financial impact of cancer. Many were keenly aware of the financial difficulties faced by people living with cancer and therefore the difference that speeding up an insurance claim could make.

One CNS said, ‘The financial part has the biggest knock on effect on patients. They still have a household to run on top of everything else.’

The CNSs that we are working with have been particularly worried that some patients are going back to work too early because they cannot afford to take more time off to recover. Many have seen patients experience a great deal of stress and anxiety due to a delay of a couple of months in their claim being processed. Rapid access to insurance money could help prevent these kinds of situations.

Making an impact
The 2014 pilot was successful and is now embedded within the Aviva service. As a result, processing times for cancer claims dealt with by Aviva have reduced from 60 days to an average of 20 days. Since the start of the partnership, 530 people have been supported to receive an estimated £33 million.
On one occasion, the Aviva claims assessing team was contacted by a claimant who had just been diagnosed with prostate cancer. His CNS got in touch the following morning to provide the necessary medical evidence required to prove the diagnosis. Following this confirmation from the CNS, Aviva was able to confirm payment in full for the claim. This was a great outcome for the claimant and for the assessor.

We continue to work with Aviva to refine the process of providing medical evidence, including specialist nurses verifying a person’s diagnosis over the phone.

The success that we have had so far is due to the work and support that CNSs have given and continue to give to the partnership. We would like to thank them for their involvement and for the considerable impact that the partnership is having for people living with cancer.

Macmillan provides information about insurance for people with cancer. You can order our booklet, *Insurance*, from [macmillan.org.uk/insurance](http://macmillan.org.uk/insurance).

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**References**


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**Further information**

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[macmillan.org.uk/macvoice](http://macmillan.org.uk/macvoice)
Encouraging patients and carers to think ahead

Dr. Kath Lambert, Consultant in Palliative Medicine, on developing a programme to promote advance care planning in Harrogate.

In 2018, the Royal College of Physicians published a report called *Talking about dying*. It discusses the challenges that doctors face in starting conversations with patients and families about what lies ahead. The purpose of these conversations is to discuss honestly what people can expect to face in the future, and to give them choices and control over the end of their lives.

Currently, discussions about end of life care often happen in a crisis or out of hours. The doctor may not have time to build up a relationship with their patient. Sometimes the person is too unwell to contribute to the discussion.

If palliative care and advance care planning are introduced early in a person’s treatment, this can:

• improve pain control, mood and quality of life

• reduce aggressive treatment at the end of life

• reduce emergency hospital admissions

• enable a person’s wishes to be respected, including their preferred place to die

• even extend life expectancy.

Aims of the programme

The Macmillan Health and Wellbeing Programme in Harrogate is well established, providing education for patients living with and beyond cancer. In 2017, the Macmillan Palliative Care Team was approached to develop a special programme for people with a palliative cancer diagnosis. The main aims of the Thinking Ahead Programme are to:

• keep patients as well as possible, for as long as possible

• encourage patients to live life to the full in a supported, self-managed way

• offer support to family members

• give advice on local services and how to access them

• provide opportunities to consider advance care planning and meet key people, who may be able to help in the future.

Programme design

The programme consists of three two-hour sessions, where two members of the Macmillan Palliative Care Team talk about:

• choice of place to die

• resuscitation decisions

• advance decisions to refuse treatment

• tissue donation

• symptom control in the last days of life.
The remaining sessions are delivered by a clinical psychologist, occupational therapist, dietitian, complementary therapist and benefits adviser.

No extra funding is required because staff are given time to deliver the programme as part of their existing roles. The programme is held at the Sir Robert Ogden Macmillan Centre. This is a comfortable and convenient location, with no additional venue costs.

Impact of the programme
In 2018, 23 people with a palliative cancer diagnosis and 17 carers participated in the Thinking Ahead Programme. Only 26% had any previous contact with the Macmillan Palliative Care Team, and 63% of patients were having active cancer treatment. This suggests that we are meeting the aim of introducing advance care planning at an earlier stage.

We use the Integrated Palliative Outcome Scale (IPOS) before and after the programme. On the first day:

- the physical symptoms that patients most commonly rated as ‘moderate’ or ‘severe’ were drowsiness, weakness and poor mobility
- 47% of patients had anxiety ‘sometimes’ or ‘most of the time’
- 71% reported family anxiety ‘sometimes’, ‘most of the time’ or ‘always’.

The programme explains how these symptoms can be managed. Other benefits that have been reported after the programme include:

- participants requesting copies of medical letters to improve their understanding
- recognising communication challenges between different services
- hospice visits to explore options for a preferred place to die
- access to additional welfare benefits
- more complementary therapy referrals.

Lessons from the programme
The Thinking Ahead Programme has been overwhelmingly well received, and participants have said that it helped them to feel more supported through this stage of their illness.

To manage increased demand in 2019, we plan to deliver the programme jointly with a Macmillan Palliative Care Team professional and a cancer clinical nurse specialist. We hope this will increase other professionals’ confidence in advance care planning. We may also widen the programme to include patients with other palliative diagnoses, such as end stage respiratory disease or heart failure.

You can watch a short film about the Thinking Ahead Programme at www.hdft.nhs.uk/services/palliative-care
Establishing speech and language therapy in palliative care

Rebecca Mears, Macmillan Speech and Language Therapist, discusses the importance of her role within a specialist palliative care team.

What would you do if you could not communicate? What if you were reaching the end of your life, but could not tell people what you needed and how you felt? What if every time you had something to eat or drink, it made you cough and feel anxious about trying again?

These are the situations that speech and language therapists are uniquely qualified to assess and manage. A project in Wales has demonstrated the importance of this role within a specialist palliative care team.

Improving quality of life

Communication is a hugely important part of everyone’s life. Difficulties in getting messages across, making needs known or expressing emotions can have a detrimental impact on people living with cancer and those supporting them.

Swallowing difficulties also adversely affect a person’s quality of life. They can result in recurrent chest infections, frequent and avoidable hospital admissions, and an untimely death. Problems with swallowing are frightening, uncomfortable and upsetting for patients, and can add to carers’ distress.

The goal of palliative care is to achieve the best quality of life for patients and their families. Speech and language therapists clearly have a role to play in fulfilling this key goal.

Demonstrating value

In October 2015, Cwm Taf Morgannwg University Health Board began a three-year project funded by Macmillan. The main objectives were to:

- examine the need for a speech and language therapy service specifically for oncology and palliative care patients
- obtain data to support the ongoing need for this service
- offer this service in acute, rehabilitation and domiciliary settings
- provide a highly specialist service to patients, with the aim of maximising their communication and swallowing potential
- identify training needs and implement training among staff, patients and relatives in relation to swallowing and eating or drinking difficulties.

Key achievements

Before the project, people had a long wait of up to 14 weeks for referral to speech and language therapy. This often resulted in poor outcomes, including hospital admissions, reduced quality of life and additional distress for patients and carers.

The project is unique in providing a highly specialist, flagship service. A review by Macmillan showed that there are no other speech and language therapist posts dedicated to supporting patients within a specialist palliative care team in Wales.

Significant changes in service provision were made over the three years, enabling improvements in patient care and multidisciplinary team working. The key achievements were:

References


Further information

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macmillan.org.uk/macvoice
an estimated 275% increase in referral rates for oncology and palliative care patients to speech and language therapy across a three-year period

the development of clear referral pathways and processes

84% of hospital ward patients in palliative care units being seen on either the day of referral or within one working day

community referrals being seen within 15 working days

improved staff confidence following training and excellent patient feedback.

Impact on patients’ lives

People with lung cancer were by far the group most commonly referred to speech and language therapy, followed by those with brain tumours, head and neck cancers and oesophageal tumours. However, people with a wide range of cancer types were referred to the service, often experiencing swallowing and/or communication impairments because of secondary brain cancer. Others may have these symptoms towards the advanced stages of their disease due to general debility and frailty.

Improvements to patient care were measured using the Therapy Outcome Measures Scale (TOMS). This ‘core scale’ examines and scores various areas, including a patient’s impairment levels, activity limitations, participation restrictions and their feeling of distress or wellbeing.

According to the multidisciplinary team, the ‘input of a dedicated speech and language therapist, for complex feeding decisions or to maximise communication for the patient to be involved in decision making, has been crucial’. The greatest achievement of the project was the impact on patients’ lives. Feedback from people with cancer and their relatives highlighted the distress caused by difficulties in swallowing or communicating. Everyone expressed gratitude for the help that they received from a speech and language therapist. One patient said, ‘I could not have had better support in this area of my care’.

Speech and language therapists have a vital role in the palliative care setting. Further work must be done to raise awareness, share learning and seek opportunities to establish the profession as a core part of a specialist palliative care team.

The Therapy Outcome Measures Scale (TOMS) scores for the speech and language therapy service.
Identifying services to support health and wellbeing

Macmillan Project Facilitator Leigh Brand on supporting people with cancer to access information and support within their local community.

As part of a recent project audit in York, people with cancer were asked to rank services that could support their health and well-being. Psychological support for people with cancer and support for their relatives ranked highly on the list of services.

Macmillan is funding a project to implement the Macmillan Recovery Package throughout York Teaching NHS Foundation Trust. The trust covers a large area, which includes about 15,000 (in 2010) people living with cancer in both York and Scarborough. Funding is set to continue until 2021 and covers a new Macmillan Recovery Package Project Facilitator role that started in July 2018. The role aims to:

• scope available support services
• identify gaps in service provision
• consider which services could support patients
• build a robust and sustainable health and well-being element of the Recovery Package.

A mini audit was carried out in October 2018. Cancer nurse specialists used data from the Macmillan electronic Holistic Needs Assessment to show which services could benefit patients, both in reality and in an ideal world. The results will influence how we develop our health and well-being service. We have also identified local services and are building links with them through our cancer information centre.

In addition to psychological support and support for relatives, other services that ranked highly were benefits advice, dietetics and complementary therapies. We know that benefits advice is already available in Scarborough and can help to relieve stress and anxiety.

There has also been an emphasis on developing patient voice, and we have met with patients through focus groups to consider which services would help them after a cancer diagnosis. We also want to be more accessible in the community and reach a wider range of people who wish to contribute their views. We had a stand in a shopping centre in Scarborough to speak informally with people affected by cancer. We also held a pop-up Well-being Café to talk to people about their experiences of services that work well, and which services could support them further.

Our team is growing and focused on ensuring that people affected by cancer have the best support available to them. This will help them to:

• be more confident in making lifestyle adjustments
• participate in their care
• feel more in control of their situation
• reduce anxiety
• improve their emotional wellbeing.

To find out more, please contact us a macmillanrecoverypackage@york.nhs.uk

Further information

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In focus: Men’s health

In this section

22  Cancer education in prisons
24  Stopping men dying from embarrassment
26  Helping men with cancer look good and feel better
Cancer education in prisons

Macmillan Senior Information Development Nurse Sue Green on delivering a cancer education session at HMP Ford in West Sussex.

HMP Ford is a category D open prison, where the prisoners are mainly men with less than two years to serve, or who have been allocated to an open prison by the Parole Board. It has an extensive education programme to help prisoners gain practical and life skills, as well as qualifications that can help them into future employment.

As part of this education programme, I was invited to give a talk about men’s health in January this year. I admit to being apprehensive beforehand, as I had no idea what to expect. But I was made to feel very welcome by prisoners and staff alike, and really enjoyed the visit.

I spoke to a group of about 16 men of all ages and cultural backgrounds. The session covered men’s health generally, but with a focus on cancer. I was unsure of people’s experience and knowledge, so began with a quiz to see who thought certain statements were true or false. For example, ‘men don’t have to be concerned about osteoporosis’ (false), ‘drinking beer can contribute to a beer belly’ (true) and ‘more men die from prostate cancer than any other type of cancer’ (false).

I also talked about common cancers, such as lung and bowel cancer, as well as cancer types that affect only men, including prostate and testicular cancer. I provided some facts about the particular cancer type, risk factors, symptoms and treatment, and we also discussed things that people can do to reduce their risk.

Literacy levels can vary hugely in the prison population.

Producing information for prisoners

At the session, I also asked for some direct feedback from prisoners on a Macmillan information booklet that I was working on called Dying, a guide for prisoners.

The booklet was originally produced in 2015, following a Macmillan project to look at the palliative care needs of people in prison. Prisoners at HMP Frankland reviewed and contributed to the booklet’s development.

While the numbers of people dying from a long-term illness in prison is low, they and their families need information about the help and support available. In April 2018, the Dying Well in Custody Charter was launched to support the provision of good end of life care to people in custody. This is thought to be the first publication of its kind and is supported by the Ambitions for Palliative and End of Life Care Partnership. Macmillan currently funds two posts for palliative care in prison, one in Scotland and one in the north of England.

One of the challenges in developing health information for prisoners is being aware of their level of literacy. Generally, prisoners are understood to have lower than average literacy levels, but this can vary hugely in the prison population.

All of Macmillan’s information for people with cancer uses plain English and avoids medical or
legal jargon. We also provide some of our information in easy read and audio book formats, as well as offering large print on request.

Macmillan’s booklet for prisoners explains what might happen as a prisoner approaches the end of their life in prison and how their symptoms can be managed. It mentions the different people who may be involved in their care and where they may be looked after. There is some information about what happens after their death and the support available for families and friends.

The librarian at HMP Ford kindly arranged for two of the prisoners to review the updated version, and generally the feedback was positive. Until now the booklet has only applied to prisoners in England and Wales, but the new edition will reflect the different laws and terminology across all four nations of the UK.

The session was well received. Those attending engaged with the presentation and I had private conversations afterwards with a couple of people who wanted to ask specific questions. I was escorted at all times by someone familiar with how the prison works, and who held the keys! Even the toilet had to be unlocked for me to use. The Education Manager was grateful for the visit and felt it was a positive and useful session.

Following the talk, I was shown round the education area. It was interesting and heartening to learn about the valuable work they do. Education can make such a difference to people whose lives have taken a wrong turn somewhere.

The current version of the booklet Dying – a guide for prisoners is available at be.macmillan.org.uk and we hope that the updated version will be published later this year.

Thank you to all at HMP Ford who made me very welcome and who contributed to revising the booklet.

References

Further information

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Stopping men dying from embarrassment

Macmillan Consultant Urological Surgeon, Jyoti Shah, on her campaign to offer men prostate cancer screenings in familiar settings.

Prostate cancer is the most common cancer among men in the UK. According to the charity Prostate Cancer UK, about one in eight men will be diagnosed with prostate cancer at some point in their lives. As a Macmillan Consultant Urological Surgeon, I have seen the emotional turmoil that the disease can cause for patients and their families.

Men often present late with prostate cancer, when it is more difficult to treat and may have spread. Many are reluctant to see their GP due to fear or embarrassment. One of the diagnostic tests involves the doctor feeling the prostate gland through the patient’s rectum with a gloved finger to check for changes. This test may be embarrassing for some men and prostate cancer is considered a taboo subject in certain communities.

My colleague, Macmillan Urology Advanced Nurse Practitioner Sarah Minns, and I decided that something had to be done to stop men literally dying from embarrassment.

The campaign
In March 2016, Sarah and I developed a new health campaign to raise awareness of prostate cancer and alleviate the ‘fear factor’.

Our ‘Inspire Health: Fighting Prostate Cancer Campaign’ began by offering men screenings and advice at Burton Albion Football Club in the West Midlands. We created a pop-up clinic at the Pirelli Stadium, where men can make 10-minute appointments. Sarah carries out the prostate specific antigen (PSA) blood test after getting patients’ informed consent, while I take a full medical history and then examine their prostate. If there are any abnormalities, we invite men for an MRI scan and possibly prostate biopsies at the hospital.

The clinic at the Pirelli Stadium is a great way to reach men over the age of 50. They have the highest risk of getting prostate cancer, but may be nervous about visiting their GP surgery or local hospital. In relaxed surroundings like their local football club, men are often more receptive to the importance of having a health check.

Our unique project got people talking straight away and resulted in eight men being diagnosed with prostate cancer. Sarah and I also set up a support group and designed a website full of useful information for people living with prostate cancer (fightingprostatecancer.co.uk).

Spreading awareness
Since then, we have taken our project to diverse venues and tried to get right into the heart of the community. Our clinics involve working with various community groups in their own environment, including Freemasons at their lodges, Rotary Clubs, other football clubs, African-Caribbean community centres, Derbyshire Police headquarters and even an Indian temple. In this way, men are already a little less intimidated when we encourage them to come forward for screening.

We also do a lot of talks to spread awareness of prostate cancer. It has been particularly rewarding to go into the Asian community, break down barriers and have an open discussion about men’s health.
All this work is carried out during our own time, as Sarah and I both have hectic full-time jobs in the NHS. Patients are never charged to attend our screening events, but we have been blessed with very generous donations to help cover the costs of running our clinics.

In parallel to our campaign work, we have raised a lot of money for Macmillan and Prostate Cancer UK.

**Life-saving impact**

To date, the Macmillan Inspire Health Urology Team has held 24 clinics in various communities. There has been a growing demand for our services and we have seen 1,904 men in total. We have diagnosed 65 men with prostate cancer (the data for many others is outstanding). Six of these men had secondary or metastatic cancer at the time of diagnosis and nine had locally advanced cancer.

We see 100 men every month in our clinics and are booked until November 2019. By the end of the year, we expect to have helped over 2,500 patients.

Sarah and I have received hundreds of letters, cards and positive comments from patients. One patient described our clinic as ‘relaxed and friendly, professional, sensitive and proficient’. Another commented, ‘This clinic has saved my life and all by two people working in their own time. So very grateful!’

It was humbling for us to be finalists for the Macmillan Innovation Excellence Award in both 2017 and 2018. We hope that our campaign will continue to go from strength to strength, breaking the taboo surrounding prostate cancer and saving even more lives.

2. Prostate Cancer UK. Are you at risk? https://prostatecanceruk.org/prostate-information/are-you-at-risk
3. Ibid.

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Sarah Minns (second from left) and Jyoti Shah (second from right) join volunteer Kelly Knopik (centre) and rotary club officials.

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**References**

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**Further information**

macmillan.org.uk/macvoice
Helping men with cancer look good and feel better

Programme Services Director of Look Good Feel Better Lisa Curtis on addressing the body image concerns of men living with cancer.

Every year, around 167,480 men are diagnosed with cancer in the UK. Body image concerns are common among people living with cancer and often a source of deep anxiety. Cancer and its treatments can change how a man’s body looks, works and feels.

Look Good Feel Better (LGFB) is an international cancer support charity that aims to help boost the physical and emotional well-being of people undergoing cancer treatment. Having provided free confidence-boosting workshops for women for more than 24 years, we have now expanded our services to support men too.

In September 2018, we introduced a new programme to help men cope with the visible side-effects of cancer treatment. These can include problems with dramatic weight change, hair loss, dry itchy skin, oral health and hot flushes.

The changes to a man’s body because of cancer treatment may happen quickly or gradually. They may be temporary in some cases and permanent in others.

Men living with cancer told us that they would value detailed information on key topics, including basic skincare, cleansing, moisturising, sun care, shaving, nutrition, fitness and oral health. There was also enthusiasm for learning through both online tutorials and group sessions.

An unmet need
Body image is the picture in our mind of what our own body looks like. It is linked to our feelings of self-worth and how we think others value us.

Look Good Feel Better spoke to men affected by cancer across the UK. Many were concerned that changes to their appearance would immediately label them as cancer patients.

Body changes can make men feel less confident, anxious about others’ reactions and worried about their relationships or meeting new people. Their sense of personal identity or masculinity may also be challenged. All too often, these overwhelming concerns are never addressed, and men are just expected to ‘get on with it’.

Bob, who was diagnosed with salivary duct carcinoma in September 2017, told us, ‘It’s not easy for us guys to talk about skincare issues or to adopt any kind of routine. Advice was short and given by well-meaning female family members but, as with all things cancer, it doesn’t always meet the need.’

In response to this unmet need, we designed our new programme to give men practical advice on coping with body changes. This can in turn improve their confidence and well-being.

Impact for men
Following extensive research, we were shocked by the lack of support for men experiencing body changes due to cancer. Based on our findings, we have created a package of support services that are available free of charge to men with any type of cancer.
These include:

• **Skin Fitness’ workshops**: these group sessions are held at local hospitals and cancer support centres in a few venues across the UK. Volunteer skincare experts and local barbers offer advice on skincare, shaving and other grooming problems related to cancer treatment. There is an opportunity to ask questions and meet others in a similar situation.

• **Manual for Men**: we worked with experts to produce a detailed booklet on managing certain side-effects of cancer treatment. Our Manual for Men includes information on skincare, shaving and grooming, oral health, what to wear, nutrition and fitness. A copy is available by email or post.

• **Tutorials**: we have a series of online tutorials featuring a barber, a stylist and a make-up artist and skincare expert. These tutorials provide tips for men undergoing cancer treatment on how to manage dry skin, disguise redness and dark circles, and dress for their shape. The tutorials teach useful techniques, such as correcting uneven skin tone, protecting the face and scalp from the sun, and re-creating missing eyebrows.

Bob attended one of our first ‘Skin Fitness’ workshops. He reported, ‘It’s so good finally to see someone is taking an interest in the care and support available to men during and after treatment for cancer. I met your team who not only empathised, but gave good advice and were very supportive.’

We have also received other encouraging early feedback from a survey. In 2018, the Look Good Feel Better programme supported about 400 men and 99% reported that they found their workshop ‘very helpful’. 74% said that they felt ‘more confident’ after the workshop and 99% would recommend it to others.

Appearance-related side-effects can have a stressful and demoralising effect on men living with cancer. We hope that many will take advantage of our new support services and become empowered to look good and feel better.
Updated

Cancer and relationships: Support for partners, families and friends
MAC17643_E01_N Edition 1
This booklet is about coping with your feelings when someone close to you has cancer. It replaces Coping when someone close to you has cancer and Cancer you, and your partner.

How are you feeling? The emotional effects of cancer
MAC11593_E05_N Edition 5
This booklet offers advice and guidance to anyone affected by cancer who may feel lonely or isolated. It discusses how someone may be feeling and provides information about further sources of support.

Worrying about cancer coming back
MAC14215_E03_N Edition 3
This leaflet is for anyone who has had treatment to cure cancer and is worried about it coming back. It has suggestions to help manage worries, uncertainties and fears, including how to get more support.

Your feelings after cancer treatment
MAC12517_E05_N Edition 5
A booklet looking at feelings after cancer treatment. It talks about the emotions someone may experience and suggests ways of dealing with these.

You can order these booklets and leaflets, plus many more, at be.macmillan.org.uk. To find out more about our full range of information, including audiobooks and easy read, visit macmillan.org.uk

From the next issue, we will be replacing the crossword puzzle with an extended update on Macmillan’s resources for people affected by cancer. This is in response to feedback from our recent survey (see page 4).

Crossword

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<th>Clues across</th>
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<td>1 Toil</td>
<td>1 Huge-eyed Madagascan monkey</td>
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<td>7 Controlling strength</td>
<td>2 High-flyer’s field of sight (4’1-3,4)</td>
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<td>8 Crisp cake of eggs whites and sugar</td>
<td>3 West Indian rock music</td>
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<td>9 Token film role</td>
<td>4 Slang for glasses</td>
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<td>10 Corrosion</td>
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<td>12 Comfort and relaxation</td>
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<td>19 A high-temperature disease</td>
<td>16 Male duck</td>
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<td>20 Gazelle</td>
<td>18 Mingled rain and snow</td>
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<td>21 Plaid or gingham fabric</td>
<td>22 Small village</td>
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Answers across 1 Labour 7 Power 8 Meringue 9 Cameo 10 Rust 12 Ease 13 Tiny 14 Onyx 15 Soon 17 Eggs 19 Fever 20 Antelope 21 Check 22 Hamlet

Answers down 1 Lemur 2 Bird’s-eye view 3 Reggae 4 Specs 5 Swimming pool 6 Groovy 7 Power 8 Meringue 9 Cameo 10 Rust 12 Ease 13 Tiny 15 Scotch 16 Drake 18 Sleet 19 Fever 20 Antelope 21 Check 22 Hamlet

New BSL videos

We’ve added two new videos to our collection of British Sign Language (BSL) videos. They contain personal stories and information from healthcare professionals. The two topics are brain tumours and neutropenic sepsis. You can find all our BSL videos at macmillan.org.uk/bsl