Katy Horton-Fawkes
Macmillan Patient and Public Engagement Lead

In focus
Professionals Conference
2018 workshops

Sharing good practice
Transforming Care After Treatment (TCAT) Programme
Welcome

Welcome to the Spring 2019 edition of Mac Voice.

In this issue, we talk to Macmillan Patient and Public Engagement Lead Katy Horton-Fawkes. Katy is combining this strategic role to improve patient engagement in her region with her existing role as a Lead Gynaec-oncology Specialist Nurse (page 10).

You can also read about how NHS Lanarkshire is using the Macmillan Values Based Approach to improve cancer care on page 12, and a new psycho-oncology service for people with cancer in Portsmouth on page 17.

Our In Focus section looks at three popular workshops held at the Macmillan Professionals Conference in November, so you can benefit from the information provided even if you were unable to attend the event last year.

And Sharing good practice highlights some of the key learnings from the Transforming Care After Treatment (TCAT) Programme across Scotland, which came to an end last year and has now been evaluated by Edinburgh Napier University on behalf of the programme partners.

Finally, a big thank you to all of you who have completed our communications survey and provided your feedback on Mac Voice. We will be updating you on the results in the next issue, but there is still time to complete the survey at www.surveymonkey.com/r/macvoice and be in with the chance to win a £50 M&S voucher or a Boots No.7 gift hamper.

Rachel Hunter
Managing Editor
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Making cancer care more personal

New Macmillan report calls for personalised cancer care to meet future demand.

The number of people living with cancer in England is expected to increase to 3.4 million by 2030. Yet, according to new Macmillan research, 60% of people do not feel confident that the government is making adequate preparations for this future patient need.

In October 2018, Macmillan released a report called One Size Doesn’t Fit All: Why we need to make cancer care in the NHS more personal.

The report examines the personal experiences of six people affected by cancer during diagnosis, treatment and beyond in the NHS today.

Katy, who was diagnosed with breast cancer in 2016, reflects: ‘You do worry with the increase in the number of patients, how is the NHS going to cope? They need to make sure they are still giving a certain level of care, regardless of the numbers of people getting diagnosed.’

We know that a cancer diagnosis means something different to everyone. A ‘one size fits all’ approach is unsuitable for delivering care. It will not address the unique differences in support needed for everyone to live life as fully as possible.

Macmillan believes that a commitment to delivering personalised cancer care is essential. One in five (20%) people believe that coordinated care is the most important factor in ensuring people with cancer get the best possible support. However, nearly one in three people feel that health and social care services are not well coordinated at present.

A new 10-year plan for the NHS

Last year, the government announced that the NHS in England will receive extra funding of £20.5 billion by 2023-24. This increased funding will support a new 10-year plan for the health service.

Macmillan has called on the NHS in England to do the following to develop truly personalised care:

- Be realistic about the level of future care needs. More people are now living for longer with cancer and at least one other condition.
- Place greater focus on quality of life and patient experience.
- Ensure effective coordination across and between health and social care settings.
- Help people living with cancer to navigate the health and care system. This includes a holistic needs assessment and a personalised care plan, which should be continuously reviewed.
- Increase the number of cancer nurse specialists to meet current and future demand. This should include investment in training and education, together with urgent initiatives to encourage retention and return to practice of the existing workforce.
- Take more targeted action on health inequalities, including consistent access to diagnosis, treatment and support.

You can read the full report at macmillan.org.uk/one-size-doesnt-fit-all

To learn more about the Macmillan Policy (Health and Care) Team or share your experience of delivering personal care contact Policy Manager Alex Callaghan at acallaghan@macmillan.org.uk
**Better conversations, better support**

A new approach to delivering personalised, integrated care.

Making sense of the different support available can be confusing and disorientating for people with cancer. Beyond the healthcare support in hospital, thousands of people have no one to talk to about their needs and don’t know who can help.

One of the objectives of Macmillan’s new strategy is for everyone with cancer to have their needs assessed regularly, and be supported to navigate their experience.

Our approach is called ‘Macmillan Right by You’. It involves identifying each person’s holistic needs, connecting up the right mix of care professionals to build the best care plan and navigating them to the right help, at the right time. This includes:

- a conversation supported with information
- a holistic needs assessment (HNA) identifying clinical and non-clinical needs
- a personalised care and support plan
- support to navigate the health and care system if needed.

These elements will be most impactful if they are delivered together, so people receive more seamless and personal support throughout their entire cancer experience. This may sound familiar as it builds on our long-standing work with the Recovery Package. Now we are building on what we have learned, and responding to external factors such as people’s needs, preferences and health system challenges. Macmillan Right by You aims to deliver integrated person-centred care across acute, primary, community and digital settings.

**Making it happen**

In 2019 we will start to test how this works in 12 locations across the UK. We will test combinations of various roles, and look at the relationships, tools and support needed. We hope this will help us better understand how to increase the number of people with cancer who feel their care is personalised and integrated. We know this helps people feel more in control of decision-making, reducing feelings of fear and anxiety.

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**In brief**

**Accessible information**

As a leading provider of health information, Macmillan strives to be inclusive across all our content. We produce high-quality cancer information across a range of formats, including easy read, translations, audio, BSL videos, Braille, PDFs and eBooks. Our new flyer, which showcases our range of accessible formats, is included in this edition of Mac Voice. You can pin it up in your service or hand it out to the people you support. You can order more copies of the flyer at be.macmillan.org.uk. Our range of accessible information is growing all the time. This year, we’ve added six new easy read booklets, one new translated fact sheet and six new BSL videos. You can see them all at macmillan.org.uk/otherformats.

**Support Line extends opening hours**

The Macmillan Support Line is now open seven days a week, 365 days a year, from 8am – 8pm including bank holidays. Our teams of trained experts offer people with cancer and those close to them practical, clinical, financial and emotional support. Natalie, a Cancer Information Support Adviser on our Support Line, says: ‘It’s making such a difference to people’s lives – they know that we’re there for them’. She has heard from many people who need support outside of the normal 9-5 working day. People with busy lives may want to talk to us about their finances or just need some help to get through the day. This valuable change to our service ensures that we can be more available than ever before. We can now meet the vital needs of people living with cancer every day of the year. Find out more at macmillan.org.uk/supportline or email slstransformation@macmillan.org.uk.

**World’s Biggest Coffee Morning**

The World’s Biggest Coffee Morning is Macmillan’s biggest fundraising event. Since it began, the event has raised more than £200 million for Macmillan. This year, more than 1,300 people registered to host their own Coffee Mornings, which have raised more than £26 million so far. We couldn’t have raised so much without our supporters and our professionals, so a big thank you to everyone who took part. The money raised will go toward helping more people with cancer to live life as fully as they can.
New Macmillan fatigue diary

We want to hear your feedback on a redesigned resource for people with cancer.

Macmillan has revamped and redesigned its fatigue diary for people affected by cancer, and is asking healthcare professionals to share their feedback on this new resource.

The diary allows people to keep track of their cancer-related fatigue. It used to be found inside our Coping with fatigue (tiredness) booklet, one of our top five most popular titles. In the new design, the diary is available as a standalone resource that can be ordered on its own and is also included within the fatigue booklet. We hope this will encourage people to use it more flexibly, for example hanging it up like a calendar or taking it along to appointments etc.

Many people experience fatigue during their cancer experience, either as a symptom, a side effect of treatment or a late effect. It is therefore really important that we get our content right, both for people affected by cancer and the professionals providing their care.

We want to understand whether the people you support do or do not use the diary, and why. We are also looking for insights on the design, ease of use, how helpful it is, and how we could make it better.

We have put together a short survey asking healthcare professionals for their thoughts on the diary. Even if you have not used it, we would still like to understand why this is.

You can fill out the survey at surveymonkey.co.uk/r/diaryprofs

What’s coming up?

April

Bowel Cancer Awareness Month
bowlcanceruk.org.uk

May

Nurses Day
12 May
rcn.org.uk/nurses-day

Dying Matters Week
13-19 May
dyingmatters.org

Sun Awareness Week
13-19 May
bad.org.uk

June

Volunteers’ week
1-7 June
volunteersweek.org

Macmillan Volunteers Conference and Awards
7-8 June
macmillan.org.uk/volunteerawards

Carers Week
10-16 June
carersweek.org

Cervical Screening Awareness Week
10-16 June
www.jostrust.org.uk
Raising awareness in Westminster

Macmillan Metastatic Breast Care Clinical Nurse Specialist Ruth Fox recently spoke about her work at a parliamentary reception.

I set up the Macmillan Secondary Breast Cancer Nurse Specialist Service at Northampton General Hospital just over three years ago. The service aims to meet the needs of people with secondary breast cancer, who the breast care team had struggled to see regularly due to the sheer volume of patients at every stage of the cancer pathway.

At a study day early on, I found out about the Partnership Pledge, organised by the charities Breast Cancer Care and Breast Cancer Now. This project came about following evidence that secondary breast cancer patients commonly do not receive the same level of support as people having treatment for primary breast cancer.

The project supports nurse specialists in carrying out a patient experience survey and then forming a focus group to identify areas of improvement.

Six months into my post, I became aware of some dissatisfaction expressed by a significant number of my patients. I wanted to get user involvement as early as possible to ensure we developed the service to meet people’s needs.

Just over 47% of 109 people with secondary breast cancer identified at that time responded to our patient experience survey. A total of 66% of responders agreed or strongly agreed that they could access a specialist nurse and 47% agreed or strongly agreed that there was a multidisciplinary (MDT) approach to their care. Although 66% agreed or strongly agreed that they had the information they required, considerably lower numbers felt they and their loved ones were receiving all the support they needed.

Key themes included a lack of continuity and inadequate local support services. Patients also wanted to know more about MDT discussion and clinical trials.

After working with service users, we have made improvements in communication within the department and are developing a photo board to make it easier to identify teams. This should help to reassure patients about the cohesive approach to their care. Other initiatives include health and wellbeing events, and a dedicated support group for secondary breast cancer patients.

As a result of this work, I was invited by Breast Cancer Care to speak at a parliamentary reception highlighting the need for more secondary breast cancer nurses. It was a good opportunity to share my experiences of setting up the service and involving patients. There are still relatively few dedicated secondary breast cancer nurse specialists, so I also wanted to highlight the difference it can make to patients to have a keyworker who specialises in their condition.

I managed to control my nerves when the patient who spoke before me described her experience of being diagnosed with secondary breast cancer. I felt if she could talk about such a personal and emotionally charged experience, then I should have no problem with sharing my work!

I thoroughly enjoyed visiting the Houses of Parliament and feel privileged to have been invited to share such a special day.

Further information

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macmillan.org.uk/macvoice
Award-winning palliative care project

Macmillan Advanced Practice Specialist Palliative Care Nurse Helen Harris on improving end of life care in emergency and acute medicine.

Our project to enable specialist palliative care nurses to work alongside the emergency department and medical assessment unit at Huddersfield Royal Infirmary won a 2018 Nursing Times Award in October.

Scottish data shows that a third of hospital in-patients are in the last year of life and 10% are likely to die during their current admission. These figures are similar in our Trust. There is also emerging evidence that patients who can access specialist palliative care nurses earlier in the disease pathway have a better experience at the end of life.

Previously, people with palliative care needs in the emergency department or medical assessment unit were waiting some time before being referred to the hospital palliative care team, and did not always get timely symptom control. Many people in the last year of life were not identified, meaning access to advance care planning was not provided.

A two-year Macmillan-funded project began in June 2017 to try and address these issues. The aim was to enable experienced specialist palliative care nurses to work collaboratively and exclusively with the acute admitting teams.

Two band 7 palliative care clinical nurse specialists, who are both non-medical prescribers, began working alongside the emergency department and medical assessment unit teams.

The project’s remit was to assess the benefits of an early assessment by specialist palliative care. From the outset, metrics were chosen to measure quality improvements and efficiencies.

Initially, we observed the different practices, pressures and needs of the two units and undertook a baseline audit. We delivered formal education to nursing staff, who have readily engaged with us regarding specific patients and embraced the opportunity to learn informally. We introduced them to the Supportive and Palliative Care Indicators Tool (SPICT) to help identify those likely to be in the last year of life.

We have avoided 13 admissions by seeing patients in the emergency department who were able to return home, or to their care home, or to access the hospice directly from the hospital.

It is estimated that 260 bed days have been saved by early specialist intervention, while preferred place of death is now achieved in 50% of patients against a national figure of around 25%.

The mean length of stay for patients seen in the project is nine days as opposed to 15 days for those seen under the traditional model for palliative care. The mean 30-day readmission rate is 9%, against 34% for the whole trust.

A focus on excellent end of life care, advance care planning and avoiding unnecessary hospitalisation has made this project a success for patients and the organisation.

References

Further information

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Improving ‘door to needle time’ for suspected neutropenic sepsis

Macmillan Acute Oncology Clinical Nurse Specialist Hilary Corley recently attended the UKONS conference to share a new approach to meeting the one-hour target.

The acute oncology team (AOT) at East Lancashire Hospitals NHS Trust was first established in 2012, with the appointment of a single clinical nurse specialist (CNS). Later that year Macmillan funded a second CNS post, and by 2015, the team had expanded to three nurses with the addition of medical and administrative support.

Neutropenic sepsis is a medical emergency, with mortality ranging from 2–21%. In 2009, the National Chemotherapy Advisory Group recommended antibiotic administration within one hour of presentation. While most NHS Trusts have protocols in place to achieve this one-hour ‘door to needle’ time, the one-hour target is often poorly met.

To try and tackle this issue, the AOT carried out a prospective audit of ‘door to needle’ time on all patients admitted with suspected neutropenic sepsis. By implementing change and re-auditing, we have successfully increased the percentage of patients receiving antibiotics within one hour from 46% in 2013 to 85% in 2017. Initial figures for 2018 show that we are maintaining a percentage of above 80% of patients.

The range of approaches that we have used to improve our door to needle time include:

• a prospective audit allowing real-time and focused education to target specialities.

• the development of a bundle for suspected neutropenic sepsis

• completing incident forms for every delay leading to regular root cause analyses, contributing to better performance

• having a pathway where suspected neutropenic sepsis patients are directly admitted, ensuring timely treatment

• extending the AOT service provision to seven days

• patient education to encourage use of our chemotherapy helpline.

All these factors have helped contribute to an increase in compliance on door to needle time and a reduced number of deaths from neutropenic sepsis within the Trust.

The challenge for the future is now maintaining, and striving to improve, these results. This is in the context of rising numbers of suspected neutropenic sepsis patients being admitted each year, as the number of systemic anti-cancer treatments being delivered within the Trust increases.

The AOT is passionate in this aim and eager to share our methods of success with other teams. Therefore I recently attended the UK Oncology Nursing Society’s annual conference in Glasgow where we displayed a poster on this subject entitled A multi-faceted approach to improving the door to needle time for neutropenic sepsis in a district general hospital.

Further information

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macmillan.org.uk/macvoice
Q&A: Katy Horton-Fawkes

**Job title**
Macmillan Patient and Public Engagement Lead and Lead Gynae-oncology Specialist Nurse

**Location**
University Hospitals Bristol NHS Foundation Trust / Somerset Wiltshire Avon Gloucester (SWAG) Cancer Alliance

**In post**
Since 2018 (14 years as a gynae-oncology nurse)

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**What does a Macmillan Patient and Public Engagement Lead do?**
My role is to work with patients and the community to ensure their voices are heard when providing and delivering cancer services. It is especially important to try and reach groups such as black and ethnic minority communities, frail and elderly people, carers, homeless people, traveller communities and those living with a mental health condition. This means engaging with a wide range of people and listening to their thoughts and feelings in an open and non-judgemental way.

Currently, I am supporting cancer transformation programmes within the SWAG Cancer Alliance. One of these is the Living With and Beyond
Cancer (LWBC) project, which supports patients after treatment has finished. We have a patient representative group, which is reviewing our current models of delivery as part of our evaluation to help ensure the project can continue across the region once current funding ends in April 2020.

What does your day-to-day job entail? A whole range of things. For example, I recently helped at a local ‘listening event’ for patients with suspected lung cancer and their carers. We wanted to know whether they felt supported and fully informed about everything that was happening to them when being investigated. Rather than completing a questionnaire, we asked them to tell us their stories of what it felt like. Listening to them explain the emotional rollercoaster of facing a potential cancer diagnosis was incredibly powerful. These accounts were then reviewed by the listening team, key themes identified and plans implemented to improve the pathway.

How did your professional background lead to this role? I started nursing when I was 19 and later completed a BSc and MSc, but I’m glad I learned the basic skills first – it reminds you to always put the patient at the heart of what you do. After qualifying, I worked in the community in London for 17 years. I did a lot of work in women’s health and especially in encouraging them to attend their cervical smears, which resulted in 94% of women in the GP practice where I worked being screened.

In April 2018, I accepted a two-year part-time secondment, as Patient and Public Engagement Lead funded by Macmillan with the SWAG Cancer Alliance. I divide my working week equally between being a CNS and the Public and Patient Engagement Lead. Initially I was concerned the two roles might be rather stressful but they dovetail very well together. I’ve nursed for over 33 years, so I have a wealth of knowledge about how patients engage with cancer services. Now, I’m learning how to combine cancer knowledge and patient and public engagement and turning that into something meaningful.

What do you hope to achieve in the two years? Success would be embedding patient and public engagement as a process within the Cancer Alliance so that it is business as usual. As a patient and public engagement community across NHS England, we hope to achieve centrally-driven standards and frameworks and the ability to measure our impact in a meaningful way. We need training and support for patient and public voice representatives. We also need to find creative ways to capture the wider patient experience, reaching diverse groups who experience poorer outcomes.

What impact do you think the role will have for people living with cancer? I hope that engaging with the public when it comes to delivering cancer services becomes a standard process. This can help people with cancer feel confident that their wishes have been considered and appropriate consultation has taken place. Patients who want to play an active part in cancer care in their local community have a point of contact and an expert to engage with.

What do you enjoy most about the role? The Patient and Public Engagement Lead role is a combination of strategic and creative thinking, which is entirely new for me and very enjoyable. At times, I have felt quite intimidated attending high level meetings about cancer services. But I’ve realised I have lots to give because I have so much clinical experience. Having practical knowledge about delivering care matters and I hope I can make a positive contribution.

‘Having practical knowledge about delivering care matters.’

I moved to Bristol in 2001 and helped set up the Bristol centre for the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS). I developed an interest in gynaecological cancer, and went on to become Lead Gynae Cancer Clinical Nurse Specialist (CNS) at University Hospitals Bristol NHS Foundation Trust and a Macmillan professional.

macmillan.org.uk/macvoice
Implementing the Macmillan Values Based Approach

Macmillan Cancer Improvement Programme Manager Lynn Mack on using the Macmillan Values Based Approach to improve services for people accessing breast cancer care.

The Macmillan Values Based Approach (VBA) focuses on behaviours that will improve the patient experience. These behaviours represent the areas that matter the most to people affected by cancer and were developed to resonate with key values for health professionals as well. Examples include ‘communicating with more sensitivity’ and ‘control over personal space and environment’.

VBA encourages teams to follow three phases for improvement:

• Discover – build up a picture of what is happening currently
• Improve – involve a wider group of people to agree an improvement to focus on
• Sustain – sustain the gains you have made and spread change.

Implementing VBA is not a one-off project, but a way of working day-to-day and something that health professionals and organisations can adapt to for their workplace.

NHS Lanarkshire has embraced this model and included organisations across health and social care to improve the experience of all patients.

Many staff working in cancer care in Lanarkshire had innovative ideas that they wanted to implement, but felt they did not have adequate time and permission or the appropriate tools and experience to help them understand and measure patient outcomes.

NHS Lanarkshire wanted to enable staff to work collaboratively and have the right skills and competencies to achieve the best possible outcomes for local people.

The work that was carried out takes into account the new integrated approach to health and social care provision in Scotland. This is aimed at supporting future public service reforms to provide safe, effective, person-centred and sustainable services.

Using VBA provided an opportunity to drive ideas forward and support colleagues to create a cultural change. It also created multiple opportunities for staff and leaders to engage with patients.

Improving breast cancer care

The breast cancer team were first to take forward VBA as they recognised various operational challenges, including variation in practice across three acute sites. In addition, there was low morale and workforce shortages at all levels.

VBA helped deliver continuous improvement with staff and patients working together to design and implement improvements. The model supported staff to assess what was really going on when patients attended the breast clinic and prepared for a breast examination. Patients and staff were asked what improvements might help, working together to identify themes and work streams before agreeing small pilots to test various changes. They were then supported to measure, sustain and spread improvements to ensure sustainability and reduce variation in practice.

For example, the team raised concerns that patients attending the breast clinic were needlessly asked to undress for a breast examination after entering the consultation room. Patients were not always offered a gown, with most being given a paper pillow case to maintain their dignity. This left them feeling exposed and vulnerable, and unable to concentrate and retain information given to them.

Further information

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Staff arranged for the delivery of mammogram gowns and have changed practice to ensure all patients are now offered a gown. The new practice puts focus on the clinical discussion with the patients in the first instance, before asking them to undress and put on the gown.

Introducing VBA as a quality improvement methodology has allowed us to listen to patients and take stock with our multidisciplinary team approach to care and signposting. This has allowed us to recognise the variety of skill sets within our workforce in the community and our partners. Although we did work collaboratively before, we now recognise the need to refer more, do this better, and look at ‘what matters’ from a patient and carer perspective.

Feedback so far
Staff have fed back on the impact that using VBA has had. For example, nurses have said that new training has enhanced their clinical expertise and allowed them to work more influentially alongside doctors. Healthcare assistants are being supported to develop their psychological awareness, and surgical care practitioners are working more closely with nurses in ways that would have been unthinkable a decade ago.

VBA aims to harness universal human emotions, such as empathy and professional aspiration, to create a sense of dynamism, excitement and academic curiosity among staff at all levels.

This work has resulted in 95% of patients being seen at clinic within 2 weeks of receipt of an urgent suspicion of cancer, with a dramatic improvement in patient experience.

The work undertaken so far within the breast team demonstrates how VBA can be used to implement change. For more information on how to apply the approach practically, and what tools and support are available, contact your Macmillan representative or get in touch at qualityimprovement@macmillan.org.uk

The Macmillan Values Based Approach is structured around eight behaviours, designed to emphasise co-productive behaviours between professionals and patients. The eight behaviours are:

1. Naming
2. Acknowledge me if I’m in urgent need
3. Private communication
4. Control over personal space and environment
5. Communicating with more sensitivity
6. Managing on my own
7. Clinical treatment and decision making
8. Getting care right
Improving outcomes for people with early stage lung cancer

Macmillan Lung Cancer Nurse Specialists Paula Deus and Kay Hughes on the benefits of pulmonary rehabilitation for people with lung cancer.

Lung cancer is most often diagnosed at an advanced stage when only non-curative treatments can be offered. In a proportion of cases, lung cancer is diagnosed at an operable stage, but surgery is prevented due to the person’s poor lung function. For example, people may present with comorbidities such as chronic obstructive pulmonary disease (COPD).

In line with the optimal lung cancer pathway, Wirral University Teaching Hospital is exploring ways to increase the number of patients in this group having surgery.

Pulmonary rehabilitation (PR) is an established service for patients with respiratory diseases, covering education, breathlessness management, exercise benefits, inhaler techniques, relaxation and pacing, respiratory medication and lung anatomy. However, people with cancer were not able to participate.

We approached the commissioners of the PR service to discuss how we could include this patient cohort. Perceptions of lung cancer were challenged as the commissioners only had experience of palliative patients, and education was required to show how PR can make a significant difference to the number of patients being cured.

One concern was whether the service would have capacity for an increased number of referrals. Additional funding was not available, so a one-year pilot was agreed to assess the impact for patients and the PR service. It was agreed that this pilot would
be for patients who had underlying COPD when diagnosed with lung cancer.

**Working together**
This project required significant collaborative working between respiratory consultants, lung cancer nurses and the lead physiotherapist in PR. Patients needed to be identified at their first appointment to benefit from the maximum number of weeks possible in the programme before surgery. The lead physiotherapist agreed to take referrals via email and for lung cancer patients to start the programme within one week of receiving this email. To meet national targets, patients need to have surgery before 62 days, so this agreement was essential.

People with lung cancer attending PR were assessed both initially and on completion of the programme to evaluate physical improvement and mental wellbeing. Overall, patients showed an improvement in their six-minute walk test, modified Medical Research Council dyspnoea scores reduced and there is evidence of improvement in the clinical COPD questionnaire.

Patients’ education and self-management also improved significantly. The Hospital Anxiety and Depression Scale assessment showed an increase in scores, which is likely due to significant anxiety surrounding a cancer diagnosis and high risk surgery.

The pilot has now been running for more than a year. Numbers have been small (seven patients in 2017 and 10 patients in the first eight months of 2018), so initial concerns about numbers impacting the service have not materialised.

There have been a number of challenges. A person’s first appointment can be overwhelming, and this is often the first time cancer has been mentioned. Spirometry is completed to diagnose underlying lung disease and if indicated, a referral to PR is made.

It can prove difficult to talk about having surgery for cancer when a diagnosis has not yet been made and this conversation can provoke more anxiety. To overcome this, cancer nurse specialists (CNS) have discussed PR with people after their appointment, and once they had got over the initial shock of diagnosis.

Patient engagement was crucial, so education was needed to help people understand the importance of attending. Feedback from patients has proved positive and all would recommend the course to others.

In the first year, of the seven patients referred, four had surgery, two patients had radical radiotherapy and one did not attend. Without the input of the PR programme and the patients’ drive to improve their performance status, it is unlikely that these people would have received potentially curative treatment.

On average, those referred have completed five weeks of PR before having surgery. A number of the patients have been keen to attend after their surgery to further optimise their health. The PR service is happy to accept these people back into the programme, with twice-weekly PR classes at various venues across the Wirral.

Following an evaluation meeting after the pilot, the PR service is happy to extend the service to other lung cancer patients who are planned for stereotactic ablative radiotherapy (SABR), or people who do not have COPD but have a curative stage cancer and lack physical fitness.

With thanks to Stuart Parkinson, Lead Physiotherapist, Pulmonary Rehabilitation.

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A joint health and wellbeing event

Macmillan Information Manager Anne Torkington on the benefits of working collaboratively with a neighbouring trust.

People living with cancer and their family, friends and carers may need information and support on a broad range of issues. Health and wellbeing events offer an opportunity to provide education and information, and signpost to a range of local services.

In May 2018, Wirral University Teaching Hospital and the Countess of Chester Hospital NHS Foundation Trust hosted a joint health and wellbeing event at the Civic Centre in Ellesmere Port for people affected by cancer in Wirral and West Cheshire. This initiative was an opportunity for collaborative working between the two trusts to optimise what we could offer and reach as many people as possible.

The joint event attracted over 100 visitors and offered signposting to various services, as well as talks from health and social care professionals on cancer-related concerns.

The educational talks explained the Recovery Package, including the value of holistic needs assessments and self-management initiatives. Speakers also presented sessions on coping with the psychological and emotional impact of receiving a cancer diagnosis and living with cancer, the consequences of treatment, and the importance of diet and physical activity. This talk incorporated a practical chair-based exercise session to engage the audience.

Having a marketplace of stalls enabled people to access a variety of services all in one place and to chat informally with a wide range of professionals and organisations offering holistic support. An added bonus of holding a joint event was that speakers, stallholders and support groups only had to prepare for and attend one event, rather than duplicate work.

The planning, organising and implementation of such events demand a huge amount of resource over a period of months to ensure a successful outcome. For very small information and support centres, the impact of this workload, in addition to providing daily support for service users, is considerable. The option to share the design of the event and divide the cost of publicity materials, hiring a venue, refreshments etc. was beneficial to both trusts, as was the saving in staff time.

The unexpected added value is the two trusts working more collaboratively and easily together on a more regular basis and appreciating the peer support and expertise from our neighbouring colleagues. It also provided an opportunity for professionals to network across the trusts.

Evaluation forms show an 88% increase in knowledge of information and support available in our local areas. One family member said: ‘Everyone in the marketplace was so friendly and welcoming. Their knowledge was excellent. This event has really helped me.’ Planning is underway for a second joint event in May 2019.

Further information

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Further information

Anne with Koren Bailey, Macmillan Information Manager at Countess of Chester Hospital, at the event.
Setting up a psycho-oncology service

Macmillan Clinical Psychologist Dr Andrew Merwood on providing psychological therapy to people affected by cancer.

Cancer can cause psychological distress, not just for patients but for their families, friends and even the professionals who look after them. NICE guidance on improving supportive and palliative care for people affected by cancer, published in 2004, outlines the importance of a ‘stepped care model’ for providing psychosocial support.

Since December 2017, I have been developing a new Macmillan Clinical Psychology Service at Queen Alexandra Hospital in Portsmouth. The hospital supports people who are newly diagnosed with cancer (over 4,000 people in the year 2017 to 2018) as well as those who are living with or beyond cancer. Research suggests that around 10% of people affected by cancer will require input from a specialist psycho-oncology service. As a lone psychologist, I had to consider how to deliver a service where demand was likely to outstrip capacity.

My service development has been guided by a Plan, Do, Study, Act (PDSA) model of service improvement. In my first two months in post – the planning phase – I didn’t offer psychological therapy to people affected by cancer and instead spent time getting to know how cancer services operate at my hospital.

Although it sometimes felt uncomfortable not to work directly with patients, I definitely consider it time well spent. I was able to meet with stakeholders, review existing evidence and policies, assemble a Macmillan Clinical Psychology Steering Group, and agree on my service objectives. This article focuses on one of these objectives – to deliver specialist, evidence-based psychological care to people affected by cancer.

To meet this objective – the doing phase – I began by offering individual therapy to people affected by head and neck cancers, which affect so many things we take for granted and are often at the heart of social relationships, such as eating and drinking, speech and appearance. This allowed me to build on a brief psycho-oncology pilot study undertaken within head and neck services at the hospital. I’m now taking this further by offering pre-operative support to patients due to have extensive surgical treatment for cancer that is likely to affect their emotional wellbeing and quality of life, working with my multidisciplinary colleagues.

Focusing on a specific group of patients meant that the service wasn’t truly equitable. To address this, I have recently begun to offer group therapy for people living life with or after cancer and experiencing high levels of uncertainty and distress.

Funded through a Macmillan Support Grant, the group uses a type of intervention called Acceptance and Commitment Therapy. This is about helping people to relate to unpleasant thoughts, feelings and sensations in a different way, so they can focus on living life by their values and doing what truly matters.

I am now undertaking the study phase of my service development. I have received 66 therapy referrals so far and the feedback from patients has been positive. I now intend to evaluate the interventions by examining changes in scores on measures of psychological distress. This will allow me to improve the service – the acting phase – before repeating the PDSA cycle all over again.

Further information

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The LGBT Cancer Programme

Macmillan LGBT Cancer Coordinator Clare Carter on improving the experience of cancer care for the LGBT (lesbian, gay, bisexual and transsexual) community.

A cancer diagnosis is life-changing. But imagine having to deal with that diagnosis, and your partner not being allowed to visit you because they are of the same sex. Or having your partner constantly referred to as your sibling. Imagine being in a cancer support group and being too nervous to talk about your relationships, as you are scared of the reaction when you say you are gay. Or being a trans woman being treated for prostate cancer.

Of course, not everyone experiences cancer in the same way, and a person’s sexual orientation or gender identity can be very relevant to a person’s experience. Work undertaken by Macmillan since 2014 focuses on understanding these differences and ensuring that LGBT people receive care across the cancer pathway that meets their needs.

In 2014, Macmillan published *The Emerging Picture: LGBT people with cancer*, which provided a comprehensive look at the landscape of cancer care for the LGBT community and the barriers and health inequalities they faced. Our project started through the LGBT Cancer Alliance, based at the Christie NHS Foundation Trust in Manchester, in 2016. In January 2018, we established the LGBT Cancer Programme at the LGBT Foundation in Manchester, led by Macmillan LGBT and Cancer Programme Co-ordinator Lawrie Roberts.

There is an emerging body of research around the health inequalities that LGBT people face, including inequalities related to cancer. The Cancer Patient Experience Surveys have showed that LGBT cancer patients have poorer experiences of cancer services than their heterosexual counterparts. From our own research, we know that one third of LGBT people in Merseyside have encountered discrimination in a medical setting.

This creates additional barriers for the LGBT community in accessing services they need.

We also know that 27% of LGBT people in the region have withheld information from medical professionals through fear of discrimination or poor treatment. This further prevents those in the community from getting the support that would help them best, particularly during such a difficult time.

As of October 2018, monitoring the sexual orientation of patients has become standard for the NHS, revealing more about the experiences and health inequalities encountered by different groups. It is crucial that Macmillan is ahead of the curve in meeting the needs of LGBT service users to ensure that nobody is left behind.

**Driving change**

The main focus of the LGBT Cancer Programme in Greater Manchester over the latter half of 2018 has been emotional support for LGBT people living with and affected by cancer. This was an area of need that was selected for further work by the patient representatives for the programme, who had mixed experiences around accessing support that felt inclusive and positive towards their LGBT identity.

By gathering together patient representatives and leaders from local services, we uncovered missed opportunities in connecting up LGBT-affirmative counselling and support (available through the LGBT Foundation to Greater Manchester residents) to patients directly via mainstream cancer services. That has now been addressed through this programme of work, and we will continue to deliver LGBT awareness training to those working in mainstream services.
In April 2018, the programme was established for the Merseyside region at an organisation called Sahir House. For the past year, we have worked hard to bring the needs of LGBT patients to the forefront of conversations in the region. We conducted a survey of local LGBT people to capture how they felt about their current physical and mental health, their experiences of healthcare settings, their experiences of cancer and their relationship to cancer-causing behaviours.

We have also been providing training for healthcare professionals and Macmillan staff to empower them to meet the needs of LGBT patients. This has involved working with other organisations and convening a stakeholder steering group to promote the needs of LGBT people with cancer, as well as targeted work within the community.

I would encourage all health professionals, wherever they are in the country and whatever their role, to start having conversations with colleagues about the needs of LGBT service users. Simple changes, such as a small rainbow flag in a waiting room or a question about sexual orientation or gender identity on a form, can make truly radical differences.

If you have any questions about the work Macmillan is doing to improve care for LGBT people, please get in touch.

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Macmillan’s report *The Emerging Picture: LGBT people with cancer* is available at [be.macmillan.org.uk](http://be.macmillan.org.uk)
Social prescribing to support people living with cancer

Macmillan Cancer Information and Support Services (MCISS) can empower people to engage in local activities and key services to improve wellbeing and quality of life.

Promoting patient self-management while supporting people to live with and beyond cancer is a key element of the Recovery Package. The Macmillan Cancer Support Centre in West Lancashire provides personalised information to people affected by cancer, and their carers, along with appropriate support to understand and act on it. Our insights into the patient experience are helping to shape our service to deliver exactly what matters most to our community.

We cover a diverse area, both urban and rural, with a population of 110,000 residents. Our main support centre is based at a shopping centre in a deprived area, where poverty is high, mental health issues are increasing, car user rates are low and public transport is inadequate. We also outreach to three villages within the borough and undertake home visits if required.

Macmillan’s impact reports show that local support can make a real difference to a person’s quality of life by improving their physical and mental health, financial situation and their ability to manage living with cancer. Our local knowledge and expertise helps us to connect people to the most appropriate service and meet people’s needs more quickly.

People with cancer have changing needs and navigating the different services available can be confusing. We work closely with the West Lancashire Clinical Commissioning Group and became part of their social prescribing pilot.

We offer everyone a holistic needs assessment to identify their worries and concerns. We can then identify solutions to support non-clinical needs and socially prescribe to local services. This initiative will be evaluated later this year.

Social prescribing is not new, and occupational therapists have been doing this for many years. It allows GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services delivered by voluntary and community sectors.

Recognising that people's health is determined primarily by a range of social, economic and environmental factors, social prescribing seeks to address people's needs in a holistic way. It aims to support individuals to take greater control of their health, particularly those with mild or long-term mental health problems, people who are socially isolated and those who are vulnerable and frequently attend primary or secondary care.

Social prescribing can refer people to a variety of activities, such as volunteering, arts activities, gardening, befriending, healthy eating advice and sports activities. We aim to encourage more people in our community to learn new skills, increase physical activity, take notice of their environment and reflect on what matters to them. The gift of giving through volunteering, connecting with new people and linking to the wider community can be very rewarding.

Further information

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macmillan.org.uk/macvoice
In focus:

PROFESSIONALS CONFERENCE WORKSHOPS

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Emotional support training

Macmillan Safeguarding and Wellbeing Manager Neil Morter on the importance of emotional wellbeing in the workplace.

Macmillan professionals are often working in very stressful and demanding roles. Our workshop at the Macmillan Professionals Conference last November focused on how to look after yourself, so you can maintain good wellbeing and best support others.

I manage the Macmillan Safeguarding Team, and ran the workshop with two colleagues, Christine Riddoch, Deputy Safeguarding and Wellbeing Manager, and Al Chester, Safeguarding and Wellbeing Officer.

We all have backgrounds in counselling and therapy, and it is our job to support everyone we work with who has a safeguarding issue – that includes people affected by cancer, the professionals looking after them and all other Macmillan staff.

We can also provide information and tools to help you promote self-care and healthy working practices, both for yourself and the people you work with.

The point of this workshop was to share best practice on how professionals look after themselves at work, and to get new ideas to take back and share with colleagues.

Why is self-care important?
First, we went around the room to get some ideas of what self-care is. It became clear that people were engaging in a wide range of activities, from walking the dog to regular sessions with a clinical psychologist at their Trust.

There are certainly things that you can do at home to help build your resilience – your ability to cope with a stressful day or unforeseen issues at work.

Ideas included:
- exercise
- mindfulness or relaxation
- identifying people you can talk to
- getting enough sleep
- giving yourself some quality time each week, for example a walk or a long bath.

Some people also said they had compulsory regular team sessions with a clinical psychologist at work, while others had optional access to a psychologist once a month.

It might seem difficult to fit these things into a busy day, week or even month. But it is really important that we don’t underestimate the impact that stress can have, and that we take steps to deal with this stress before it builds up and becomes unmanageable.

The professionals attending the workshop identified that self-care can help you to:
- be as effective as you can be at work
- avoid compassion fatigue or burn out
- reduce negativity within a team, which can impact service quality
- recognise your limitations and when you need support.
Promoting self-care in the workplace

We then asked professionals to think about current measures in their workplace to promote and support emotional wellbeing. A range of initiatives were mentioned, including:

- clinical supervision
- awaydays and regular team meetings
- counselling services through occupational support
- informal peer support
- Employee Assistance Programme

However, the support available greatly varies from trust to trust, and many people were not given the time to make use of these initiatives in working hours, or missed out due to lone working arrangements.

While getting the right support in place should not rest on health professionals’ shoulders, we wanted to give people some ideas and questions to take back to their managers. We asked people to think about the following questions:

- Do you have self-care procedures within your team?
- Does your Trust have a wellbeing strategy?
- Can you help develop a wellbeing champion network promoting healthy practice?
- Is self-care considered part of learning and development by your Trust?

Promoting a culture of self-care can foster a more positive working environment, which can boost productivity and improve service outcomes.

Mental Health First Aid has free downloadable resources for mental health in your workplace, including film clips, infographics and guidance for line managers. Find out more at mhfaengland.org

Supporting others

The final section of the workshop focused on how you can support others – whether you are helping a colleague, a patient or someone close to you. Here are some of our top tips:

- Focus on listening rather than saying the right thing
- Be non-judgemental
- Sometimes silence can be comforting
- Ask what you can do to help – this can be empowering
- Encourage self-help – by using some of the techniques we have talked about here or seeking professional help.

Most importantly, remember that the Macmillan Safeguarding Team is here to help, whether you need support for yourself or for someone else. You can get in touch via email at safeguarding@macmillan.org.uk, or if it’s urgent, call us on 07595 002 022 or 07793 579 375. Someone is always available on one of these phone numbers 24 hours a day, seven days a week.
Showing your value

Macmillan Chief Economist Mike Haslam on using data to make the case for funding in a difficult economic climate.

Macmillan professionals will know more than most about the financial pressures currently facing the NHS, and the difficulties in getting new funding, or extended funding, for roles and services.

At Macmillan, a key part of our work is to help fund these services at the outset, and to provide the data and evidence required to establish services permanently.

Whether you have received initial funding from Macmillan or not, many Macmillan professionals will at some point need to put together a business case to ensure their service is continued, with the right workforce in place to support it. And data can be vital to getting that green light from a trust or commissioner.

That's why we wanted to take the opportunity to give some advice about how to use data to make a business case at the Macmillan Professionals Conference last November.

Cost-benefit analysis

All of us use economics and economic theory in our day-to-day lives, often without realising. For example, when deciding what to do at the weekend, you might weigh up the pros and cons of the various options you have to make a decision - for example enjoyment, cost, time etc. This is what economists call a cost-benefit analysis.

Cost-benefit analysis, alongside data and evidence, can help persuade senior managers and executives of the value of our work.

To produce a cost-benefit analysis, you need to weigh up the costs and the benefits of an intervention to see whether it is worth doing or continuing.

You might also take into account:

- the consequences of not doing the intervention
- the effectiveness of the intervention
- return on investment
- the social value that the intervention brings.

The types of costs and benefits that you consider are likely to be the impact on people's experience of care and health outcomes, the impact on treatment costs, and any wider impacts that the intervention has, for example on people's ability to stay in work. Ideally, you need to find a way to quantify this, but this can often be challenging.

To develop a cost-benefit analysis, and determine the costs and benefits that should be included, think about the activities you are doing, and what you aim to achieve by doing them. In general, interventions will have more than one aim. For example, a care plan can determine someone's needs and how best they will be met. The discussion leading up to the plan, and the plan itself, can help people get access to services, treatments and activities that are more likely to meet their needs. This should improve their experience of care and ability to self-manage, and could reduce costs to the system in the longer term.

You can also talk about what would happen if the intervention didn’t happen, or your role or service didn’t exist. In economic terms, this is called the ‘counterfactual’. What would happen if you did nothing? This is the most robust comparison you can do, but while it is easy to describe, it can be difficult to measure. Examples of areas to consider could include more demand on GPs’ or clinical nurse specialists’ time.

Further information

Click here for full article

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What data can you use?
Ideally, you want to supplement your business case with robust data, setting out the size of the likely (or observed) impact on people’s experience, quality of life and the impact on the NHS.

However, it can be a challenge to get hold of data, and if this is not available, you might want to think about whether it is possible to gather data yourself. Ideally, you would start this early in the project. While it is possible to collect data later on, it can be much more difficult, and you may not be able to access the data you want.

It is important to identify how you can get hold of data. You could try to build links with business intelligence analysts at your Trust, who may be able to help. Or you could reach out to academic institutions, who might be willing to support your project pro bono or for a low fee.

Case studies can also help if data is not available or of poor quality. They are great at illustrating the benefits of what you do, and if you can align case studies with the overall aims and rationale of your activities, they become more powerful. You might also be able to use case studies to show what happens without this particular role or function. Finally, other teams or areas of the country may have already implemented this intervention, and might have data and evidence you could use.

In summary, the key questions to think about when making a business case are:

• What do you want people to know?  
  What do people need to hear?

• Can you create a convincing rationale?

• What data or evidence might you be able to bring in?

• Can you get support from senior or influential stakeholders?

If you have a business case to make and would like more detailed advice and support, you can contact the Macmillan evidence and evaluation officer at your local Macmillan office.
What’s new in cancer

The latest updates on new cancer treatments, genomics and the potential impact on people with cancer and the professionals that support them.

This workshop showcased the recent evidence and insight that Macmillan has produced around personalised treatment. It also explained the work we are doing in collaboration with acute oncology professionals to raise awareness of the impact of new treatments for people living with cancer.

Cancer treatments are rapidly developing, making it challenging for health professionals to stay on top of what is happening in order to best support people living with cancer. In this session, we explored the importance of conversations about new treatment options, how to make sense of the reams of information out there about research developments, and provided tips on what information professionals can share with people living with cancer.

The workshop was attended by more than 100 professionals ranging from clinical nurse specialists, allied health professionals, information managers and support workers and even a paramedic. It was delivered by Dany Bell, Macmillan Specialist Advisor for Treatment and Recovery, Ellie Bloom, Macmillan Strategic Analyst and Philippa Jones, Macmillan Associate Advisor for Acute Oncology.

Dany spoke about the hot topic of genomics and what cancer teams need to know about consent for genomic testing. Philippa gave expert information on immunotherapy treatments, as well as side effects and how to manage them. Ellie presented an overview of our evidence and insight report, which covers the current landscape of cancer treatment and how it is changing, as well as the impact for people living with cancer and the workforce in supporting them.

Evidence and insight
Ellie began the workshop by talking through some of the top-line findings of Macmillan’s latest evidence and insight report: The impact of new personalised cancer treatments. This explores the impact that new treatments are having on people living with cancer and the cancer workforce. It is a useful read for an introduction to some new concepts, or for anyone who wants to delve a bit deeper into the topic.

The report highlights that personalised medicine has the potential to impact all aspects of cancer care, from screening and diagnosis, to staging and treatment. Many new treatments, such as immunotherapies, are available for those on clinical trials, and particularly for those with cancer that currently cannot be cured.

There are more and more treatments coming out of clinical trials all the time, so we are seeing a more rapid increase that has largely been driven by a rich pipeline of targeted treatments. However, there are also many barriers to participation in clinical trials, including patients’ misconceptions and inequalities in access. It was valuable to share this insight and answer questions.

These new therapies bring with them a different range of immune-related side effects, and largely unknown long-term effects. This has implications for the workforce: it impacts chemotherapy nurses who are delivering many of these new treatments, as well as the broader cancer workforce who need to recognise these different side effects and ensure patients get timely support. You can read the full report at macmillan.org.uk/newtreatments

Genomics
Dany then provided an overview of the 100,000 genomes project, and our collaboration with NHS England and Health Education England to develop information...
for patients and professionals to help them have conversations around gene testing and cancer. We also shared the exciting news that we are developing a personalised treatments web page, where all the relevant information will be available in future.

New therapy options
Philippa then highlighted the cancer types where we have new treatments, and the types where treatments are in trial phase and will be emerging. We asked participants to name as many immunotherapy drugs as they could in five minutes – the highest score was six! She also shared the message that we shouldn’t forget established treatments that are still in use and sometimes used in combination with immunotherapy or are first line with immunotherapy second and third line treatment. And of course, all treatments, established and new, may cause problems.

The routes of delivery for new treatments are no different to established treatments, but Philippa provided a reminder that:

• the assessment and management of side effects is different and needs attention

• the emotional and psychological impact can be difficult to manage due to the media often labelling new therapies as wonder drugs – but they don’t work for everyone.

There was lots of interaction and engagement with the professionals who attended.
The Macmillan Organiser
MAC15835_E03
Edition 3
The new Macmillan organiser includes a copy of *The cancer guide* and My records for recording key contacts, appointments, medication and symptoms. There is also space for keeping appointment letters or other information resources.

Coping with fatigue (tiredness)
MAC11664_E08
Edition 8
Aimed at people who have fatigue as a result of cancer or its treatments. Looks at why fatigue arises and how to deal with it at work and home. Includes a section for carers.

Cancer treatments and sepsis (new)
MAC17281_E01
Edition 1
A new leaflet explaining what sepsis is – this is also included in our Understanding chemotherapy booklet.

Understanding risk-reducing breast surgery
MAC11680_E06
Edition 6
An explanation of risk-reducing breast surgery for women who know they have an increased risk of developing breast cancer. Explores potential risks, recovery process and emotional impact.

Understanding breast reconstruction
MAC11660_E13
Edition 13
Describes what reconstructive surgery involves, its risks and benefits, and the different options available.

Understanding soft tissue sarcomas
MAC11654_E10
Edition 10
Explains soft tissue sarcomas, covering causes and symptoms, diagnosis, staging and grading, treatments and clinical trials, plus emotional, practical and financial issues.

You can order these booklets and leaflets, plus many more, at be.macmillan.org.uk, or call 0800 500 800. To find out more about our full range of information, including audiobooks and easy read, visit macmillan.org.uk

Crossword

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Clues across
1 Slow down (6,5)
7 Inheritance chromosome
8 Tynesider
9 First note of musical scale
10 Persuade
11 Pours fat over roasting meat
13 French brandy
16 Mature female cat
18 Married woman’s title
19 One part of a TV serial
20 Ocean liner
21 Caramel-coated fruit on a stick (6,5)

Clues down
1 Afternoon nap
2 A plus sum in the bank
3 Evenings
4 Small tenant farm in Scotland
5 The belly
6 A doubting Thomas
11 Legacy
12 USA law enforcer
13 Snapshot taker
14 Tittle-tattle, chatter
15 Guidance, words of wisdom
17 Looped rope to tether ponies