‘Work is a fundamental part of life for most people. That’s why our service is important.’

Gerard McFeely
Macmillan Consultant
Occupational Therapist

In focus
Mental health and cancer

Sharing good practice
Action learning
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Macmillan at Edinburgh Libraries

This partnership between Macmillan and City of Edinburgh Council is supporting communities across the city.

Every day, six people in Edinburgh hear the devastating news that they have cancer. With the number of people living with or beyond cancer set to almost double by 2030, Macmillan wants to help make sure that they can live the fullest life possible.

The Macmillan Cancer Information and Support Service is staffed by specially-trained volunteers and currently operates in two locations: Central Library and Craigmillar Library. It will soon be available at six libraries in the city, with four more sites opening by the end of 2017.

The service provides information on all aspects of cancer, a listening ear, emotional support and access to other services, and is part of a more than £1m investment by Macmillan in Edinburgh. This investment has also funded services for people affected by cancer in the city including an exercise and wellbeing programme called Move More, welfare benefits advice and a vocational rehabilitation service to support people in work.

The volunteers staffing the service are trained in cancer awareness, listening skills, giving support, signposting to further help and services and dealing with difficult situations.


‘Thanks to our partnership with City of Edinburgh Council, people affected by cancer can access up-to-date, relevant information and someone to talk to.

‘We know it can also be difficult and costly for people affected by cancer to travel so having this support available locally in relaxed and friendly venues like libraries can make it much more accessible.’

Culture and Sport Convener, Councillor Richard Lewis, said: ‘Our libraries provide for local communities in so many ways, from social engagement to information access, and now we are able to extend this to offer support and guidance to those affected by cancer, thanks to investment from Macmillan Cancer Support.

‘Most of us will be touched by cancer at some point in our lives, so it’s fantastic to know that this excellent service is available to give help and advice on a local level at such a difficult time. We have already seen people benefit from its introduction at Central Library and Craigmillar Library and I look forward to seeing it expand to other communities in the city.’

Cancer Support Scotland is another partner in the service and will offer counselling services and mindfulness courses. The counselling service is available now at Craigmillar Library and will be provided in two more library locations when the Macmillan at Edinburgh Libraries programme is rolled out.

More information
Contact Michelle Gallacher, Communications Manager Scotland, at mgallacher@macmillan.org.uk

The Edinburgh Libraries project team
In brief

Guidance on long-term consequences
Nearly 43,000 people are diagnosed with a colorectal or anal cancer in the UK each year. With treatment, 60% of them will survive for more than five years, but some may suffer from consequences of treatment. Our new guidance for professionals offers advice for clinical management including helping people to self-manage.

Order or download free copies from be.macmillan.org.uk/cot

New Macmillan advertising
By now you may have seen or heard our new advertising on TV, radio, print and online. It marks a departure from the ‘Not Alone’ campaign, which we’ve used for the last four years, and features the central message that life with cancer is still life, and Macmillan helps people to live it. Thanks to all the Macmillan professionals whose input has helped us develop this new approach.

£75 million
That’s how much Macmillan benefits advisers in Wales have helped to secure in benefit payments for people affected by cancer since 2010 – and counting. People can search for local advisers on our website at macmillan.org.uk/inyourarea or access the welfare rights team on the Macmillan Support Line by calling 0808 808 00 00.

Celebrating practice nurses

Rebecca Billingsley, Macmillan Practice Nurse Facilitator, was a finalist at the 2017 Solihull Together Awards in March.

Rebecca was nominated in the category of Health Professional of the Year. Another finalist in the same category was Jacqui Rea – a practice nurse based in Solihull – who completed the first Macmillan Cancer as a Long Term Condition course that Rebecca facilitated.

The course for practice nurses was initially developed by Macmillan Alumni GP Advisor Dr Charles Campion-Smith and piloted in 11 areas. As part of the training, nurses gain the skills to support elements of the Recovery Package: a series of interventions to improve outcomes and coordination of care for people living with cancer.

Rebecca explains, ‘An initial pre-course evaluation identified that the nurses did not feel confident to discuss issues around cancer, but the same question posed at the end of the course showed a total contrast.’

‘One element of the Recovery Package that the course helped nurses to deliver was Cancer Care Reviews (CCRs). These are follow-up appointments in primary care, no longer than six months after treatment has finished, to provide support and facilitate self-management.

Rebecca says that Jacqui has done a fantastic job of working within time-constraints that can pose a barrier to carrying out CCRs: ‘Jacqui has shown amazing determination to make these reviews part of her practice. She now has protected time on Wednesday afternoons to undertake health care reviews. She is exploring offering a chronic diseases clinic to patients with other co-morbidities, truly seeing the patient holistically. Recently, she has run her first breast cancer support session at her surgery, which proved very popular. There are more planned for later in the year.’

As a Macmillan Practice Nurse Facilitator, Rebecca’s role includes working with Macmillan GP Facilitators to enhance communication between primary, secondary and tertiary care. She supports practice nurses in her area in learning about cancer and facilitates implementation of the Recovery Package.

More information
Contact Joe Bates, Communications Officer, West Midlands, at jbates@macmillan.org.uk
Talking about the end of life

A new Macmillan report is encouraging earlier conversations about death.

Just 1% of people with cancer want to die in hospital. Yet of those who die from cancer each year, 38% (more than 62,000 people) die in hospital.

Well over half of the UK population think we don’t talk enough about death, which is preventing people from having their dying wishes met. Macmillan believes that having these conversations earlier could be key to improving this.

The new Macmillan report, ‘No regrets: how talking more openly about death could help people die well’, aims to make people aware that they have choices around their future care, which can be managed with early conversations.

In the introduction to the report, Adrienne Betteley, End of Life Care Specialist Advisor at Macmillan, says, ‘We want everyone, where possible, to have a death that's pain-free and in the place of their choosing. This is where the power of talking about death in advance is crucial. As many of the medical professionals working in clinical roles will already know, having open and honest conversations about dying can be the first step towards having a ‘good’ death.

Adrienne also says, ‘Macmillan knows that not everyone who needs to is given the chance to have these vital conversations. We also know that, too often, people are not dying where they would like to, or in some cases do not even know they get a say on what happens around their final days. We’ve carried out research into possible reasons for this, exploring attitudes towards dying – among the general public, and people who have cancer – and our initial findings have been illuminating.’

More information
To read the report, visit tinyurl.com/no-regrets-report
You can also find out more about our campaign to improve choice at the end of life by visiting macmillan.org.uk/endoflife
Macmillan Health and Wellbeing Service in Northern Ireland

Since 2012, Macmillan Cancer Support in Northern Ireland has invested in a health and wellbeing service to increase access to quality cancer information within local hospital, health and social care and community settings. Sharon Clarke, Macmillan Health & Wellbeing Co-ordinator for SHSCT, Caroline Davies, Macmillan Support Worker, and Ruth Thompson, Macmillan Partnership Manager, talk about the positive impact of their work.

Tell us about the health and wellbeing service

Ruth: We identified gaps in the provision of cancer information and support, something that particularly affects people living in rural areas across Northern Ireland. SHSCT has a largely rural population of almost 370,000. It’s an ethnically diverse and fast-growing population, and it’s increasingly important to ensure that people (especially those who are hard to reach) have access to quality information and support services that can make a positive difference – improving their wellbeing, financial situation and ability to live life with cancer.

Sharon: Working with Caroline, Trust colleagues, and our volunteers, we are building proactive relationships with partners, for example, local libraries, GP practices, voluntary sector organisations, LGBT, BME and Travelling Community groups, to increase awareness and uptake of local services. We also have the invaluable support of local Macmillan professionals including Mary Haughey, Macmillan Service Improvement Manager, and Gerry Millar, Macmillan GP Advisor for Northern Ireland, with whom we work very closely. It’s all about identifying positive opportunities to work together simply and effectively.

What impact is the service having?

Sharon: We are delighted that the service has achieved all three MQEM, MQuISS and MVS awards to date. Our Macmillan Information and Support Centre at Craigavon Area Hospital has supported over 2,300 people since opening in 2014. In the last year, visitor numbers have doubled and referrals to the service from health and social care professionals have tripled. We have developed invaluable relationships with local GP practices – all but one in SHSCT now have a Macmillan information display. Our health and wellbeing events (e.g. breast, lung and skin cancer), which reach people in many settings, have resulted in half of all referrals to our local Move More scheme to date. We’re seeing uptake of services, information sharing, increased awareness and genuine collaboration.

What do you find most rewarding about your role?

Caroline: Being a listening ear for people who are living with cancer, and their friends and family, is so rewarding. It’s a privilege to meet them at the information and support centre, and help them during a challenging time.

Sharon: Making valuable connections with people is so important to the work we do. There are many groups and organisations within SHSCT who can benefit from working together, and help those most in need. It’s always rewarding to ‘join up the dots’ and identify areas where we can collaborate and support people living with cancer.

More information

Contact Sharon Clarke, Macmillan Health and Wellbeing Co-ordinator, at sharon.clarke@southerntrust.hscni.net

Pictured left to right are Ruth Thompson, Macmillan Partnership Manager; Caroline Davies, Macmillan Support Worker; Fiona Reddick, Head of Cancer Services, Southern Trust; Sharon Clarke, Macmillan Health & Wellbeing Co-ordinator; and Lynne Smart, Acting Head of Health Improvement, Southern Trust.
Empowering and enabling through advocacy

Older people affected by cancer in Dorset are getting one-to-one support that meets their individual needs.

Macmillan’s own research demonstrates that 64% of new cancer diagnoses occur in older people (aged 65+). The Older People’s Cancer Advocacy Alliance (OPAAL) identified that this older age group are less likely to be offered active treatment and are also less likely to approach healthcare professionals about their concerns.

Dorset Macmillan Advocacy was born out of a lottery funded pilot project in 2013 by OPAAL and is aimed at providing independent one-to-one support for older people affected by cancer. Macmillan saw the value of this and have been supporting the project since 2014.

A cancer diagnosis brings a whole raft of new individuals into a person’s life, each with an important role to play in their care. Advocacy is a unique kind of support because the person themselves determines their advocate’s role in their life. An advocate is also in a unique position as they are completely independent from everything else in the patient’s life, be that friends, family or healthcare professionals.

**Issue-based support**
An advocate can support with straightforward issues such as having someone to attend appointments with, or complex issues such as dealing with housing or employment concerns that have arisen due to changes in circumstances brought about by a cancer diagnosis.

Here in Dorset, we have nurtured relationships with the Site Specific Clinical Nurse Specialists in our local hospitals as they are in the unique position to identify patients who need extra support. Often people that most need support are precisely those that are least likely to seek it, so being referred to the service by a trusted healthcare professional might be the only way that they access advocacy. A lot of older people affected by cancer have family that wish to support them but due to the nature of modern life, they live many hours away. An advocate can bridge that gap and be there to offer support.

The Cancer Advocacy Service hinges on Peer Volunteer Advocates who are trained and supported by staff. The volunteers are the most valuable asset we have as they all have experience of cancer themselves and are ‘experts by experience’. Introducing a person affected by cancer to a volunteer and seeing them realise that their Peer Advocate truly understands what they are going through is a great pleasure.

Visit dorsetmacmillanadvocacy.org to find stories and short films describing the difference that cancer advocacy support makes.

**More information**
Contact Jen Rimmer, Dorset Cancer Advocate, at jenny.rimmer@dorsetadvocacy.co.uk

Pat (right) and her husband’s cancer advocate, Karen (left). You can read Pat’s story at dorsetadvocacy.co.uk
Partnership award for physical activity programme

Physical activity programme Move More Aberdeen has won a prestigious award in recognition of its positive approach to partnership working.

Move More Aberdeen, a project funded by Macmillan Cancer Support and delivered by Sport Aberdeen, was awarded the Aberdeen Council of Voluntary Organisations (ACVO) Award for ‘Connecting and Collaborating’ in recognition of the impact of partnership working across cancer services in the city.

Since the inception of the programme, Move More Aberdeen has worked closely with NHS Grampian, CLAN Cancer Support and Paths for All to embed physical activity into the cancer care pathway. The programme has received 274 referrals since it started in January 2015.

Macmillan Development Officer Josefine Björkqvist is the coordinator for Move More Aberdeen. Josefine says, ‘Move More Aberdeen has already had a hugely positive impact on the lives of many people living with and beyond cancer in Aberdeen and through continued collaboration we aim to make physical activity an integral part of the standard care and treatment of everyone affected by cancer.’

Macmillan Partnership Manager Joanne Adamson says, ‘This award reflects the hard work and dedication of the Move More Aberdeen team and highlights the importance of partnership working to ensure that people with cancer are given the support they need to get back into physical activity.’

Participants in the Move More Aberdeen programme can choose from a range of activities including walking groups, gentle movement, gardening and circuits-based activity classes.

In the past year, the programme has worked with NHS Grampian and local cancer charity Friends of ANCHOR to introduce a gentle exercise group at the radiotherapy department in Aberdeen Royal Infirmary. This is a pioneering service, raising the profile of physical activity in the clinical environment and improving access to physical activity for cancer patients having radiotherapy treatment.

Gordon Lees, Move More Aberdeen participant, said, ‘During a long course of radiotherapy I noticed how very much less mobile I was becoming but I felt too tired to do exercise. Luckily, the carefully chosen, gentle seated exercises at the radiotherapy department had started up during my last two weeks’ treatment. ‘Very quickly, my stiffness began to disappear, my coordination and the strength and range of my movements increased.’ Gordon has achieved further improvements in balance, general fitness and sense of well-being with the Move More Aberdeen circuits.

More information
Contact Josefine Björkqvist,
Macmillan Development Officer,
at nhsg.movemoresa@nhs.net
Evaluating cancer information

The Cancer Information Development team has been exploring new ways to capture people’s immediate feedback on our range of information.

In May we hosted an online survey on many of our prostate cancer web pages. This short survey was open for three weeks and we had over 60 responses from a range of people including people living with cancer, family members and friends. This was followed up with a survey on many of our kidney cancer web pages. We’ll be rolling the survey out for other content areas over the next few months, guided by our content revision schedule.

What are we asking?
We’ve been asking people how easy it is to find the information they need online. We asked whether it was helpful, and if not why not? Was it easy to understand? How did it make people feel after they read it? Did they feel it was relevant for them, and could they think of any ways we could make improvements?

The prostate survey told us that:

- 60% found what they were looking for
- 32% found some but not all
- 8% didn’t find what they were looking for
- 51% said the information was very helpful
- 46% said the information was somewhat helpful
- 43% said the information was very clear
- 41% said the information was clear
- 14% said the information was fine

After reading the information:

- 45% felt positive
- 36% felt supported
- 33% felt less anxious
- 27% felt both more in control and reassured
- 6% felt both frightened and upset

Next steps
Macmillan’s content developers will consider any key feedback we capture alongside our usual patient and professional review process when reviewing information. Our Quality and Evaluation team will also be looking to spot trends across content areas to get a wider view and identify areas where we can improve.

With a six-month lead time for reviewing resources, we have designed the surveys to go live early in the revision process to give us enough time to consider the responses at the very beginning of each review.

Help us evaluate our information
We’d love to hear your feedback on our cancer information, as well as any comments from the patients you work with. Please email Lynn Fox, Macmillan Quality and Evaluation Officer, at lfox@macmillan.org.uk with any feedback and include your contact details if you’d like us to call you back for a more in-depth chat.
A tribute to Nick Coyle

After receiving support from Macmillan, Nick gave back through the written word.

When classics teacher Nick Coyle was diagnosed with cancer, he was impressed by the support we gave him in navigating the benefits system and employment law.

After becoming too ill to work, he decided to fulfil his dream of becoming a writer and to give back to Macmillan. His blog, ‘Modern Twaddle’, and his collection of short stories called ‘Another Normal’ have raised more than £3,000 for Macmillan, far exceeding his original £500 target.

Nick sadly died in February 2017 at the age of 32, but he continues to raise vital funds for Macmillan through his writing.

The stories are very funny, often moving, and are testament to a man much loved by his friends and family. Nick has written numerous short stories including ‘Another Normal’, ‘Eat, drink and be merry’ and ‘Superhero’.

More information
Visit Nick’s website at moderntwaddle.com

Reviewing books for Macmillan Cancer Support

Since we started recruiting volunteers to review books in 2007, more than 1,500 people have written reviews of more than 450 books.

Macmillan’s book reviews cover personal experiences, bereavement, cookbooks, children’s books, graphic novels and poetry.

Our reviewers have personal experience of cancer. This may be as a patient, a carer, family or close friend. We also need healthcare professionals to review books so please get in touch if you are interested.

The reviews help people make an informed decision about which books to read and, perhaps more importantly, which to avoid. These reviews can be found at publications.macmillan.org.uk

Books and reviews are also featured on our Online Community Book Club. Visit community.macmillan.org.uk and search under the tag ‘book club’.

‘It took me a while to discover useful books to read and I feel I would have had an easier ride through my treatment if I had known about them sooner.’
Breast cancer patient

‘I’ve found it really stimulating – can’t let chemo cave my brain in!’
Breast cancer patient

‘I am enjoying reviewing and on the back of it have been better able to recommend items.’
Macmillan Cancer Information and Support Coordinator

More information
If you are interested in reviewing a book, please contact Sue Hawkins at shawkins@macmillan.org.uk

We advertise details of books for review on the Volunteering Village at volunteering.macmillan.org.uk You can register as a Cancer Voice to receive...
Gerard McFeely

Job title
Macmillan Consultant Occupational Therapist

Location
Edinburgh Cancer Centre

In post
Since 2015

Contact
gerard.mcfeely@nhslothian.scot.nhs.uk

Gerard has recently co-authored a systematic review about work and cancer, which was published in the International Journal of Therapy and Rehabilitation, May 2017, Vol 24, No 5. It found a greater need for formalised evidence backing up the impact of vocational rehabilitation services for cancer.

What is your professional background?
I have been an occupational therapist for 30 years, working in many different NHS wards, psychiatry services and A&E among other areas.

Vocational rehabilitation – essentially evidence-based interventions to support people who have health problems in overcoming barriers to working – is an old concept in occupational therapy. In recent years, it has gained greater prominence within the government’s agenda because of welfare changes. They want people to be in work. At the same time, cancer is now becoming a long-term condition for many people, which led us to modernise our services.

Evidence from Macmillan suggests that work is the next most important thing to people with cancer after treatment, survival and family. We have to ask ourselves as cancer support professionals, do we want to put all our effort into treating people if we’re then not going to help them to continue being able to do things that are important to them? Work is a fundamental part of life for most people. That is why the Macmillan Cancer and Work service we run from Edinburgh Cancer Centre is so important in supporting people with cancer who have a preference to work.
How did the service start?
The service originated two years ago, but we spent about three years doing preparatory stakeholder work with Macmillan to scope the need. In NHS Lothian we were running work support services for all health conditions, but knew there was a huge gap in the provision for cancer – we were only getting five cancer referrals a year. We thought that was odd. We got the stakeholders in the room and spoke to Macmillan about putting boots on the ground and setting a service up that people with cancer could contact directly.

The key thing was to use the evidence from Macmillan, including the need for regional leadership. Two years after starting the service we have met our targets, and now we are doubling our targets for the next two years because we realise the demand is greater. We’re going to increase and expand and seek sustainability from within NHS budgets after the initial generous funding from Macmillan.

We initially set out to cover the South East Scotland Cancer Network (SCAN) and decided Edinburgh Cancer Centre was a good place to start. It was more cost-effective to take a regional approach, because patients come from many areas of their treatment. Our reach is helped through telephone and web-based assessments and following up as needed with more specific clinical services. This is quite challenging within our resources, but we think we’re going to improve this over the next two years. I also oversee the Department for Work and Pensions’ Fit for Work service and the Scottish Government’s vocational rehabilitation service – so I use existing enrolment and assessment on the phone, and real-time, web-based chats as part of these services that we can tap into.

What kind of support do patients need?
Sometimes patients need light touch case management and advice. A lot of people present with a problem. They come with a story about their life and what they’re experiencing socially as well as medically. We are following the national agenda in trying to help people holistically with their needs. Some people will need more occupational therapy work-focused assessment. Others will need employer engagement support.

We see all patients at all stages, from newly diagnosed to people who have been living with cancer for some time. We also see people who are about to start treatment, but who are trying to continue working. We need to listen and give advice at the right point. If I ask someone what the importance of work is to them, it’s probably the wrong question. It’s better to say ‘what are your priorities right now and how can we help?’. They may say, ‘I feel put upon at work’ or ‘my employer won’t make reasonable adjustments’ or ‘I don’t want to disclose that I have cancer to my employer’.

And we are guided by the narrative they present. A lot of patients just need advice and then feel empowered to tackle the problem. They can then come back to us and we can increase our input if necessary, which sometimes unfortunately includes serious cases such as supporting people facing disability discrimination.

What have been the challenges?
Change management can include difficult conversations with established services. Some services may not currently offer work-related support or be unsure of how to proceed in that area of practice. My job is to change the system in that way. Having Macmillan in my job title helps to make this possible and opens doors.

What have been the biggest successes?
I would say reach is our biggest success. I didn’t expect 10% of those we’ve helped to be young people and teenagers with cancer, or for 20% to be carers and relatives of someone with cancer. We have people who might be out of work, struggling to stay in work or who want to return to work. We are reaching a broad range of people affected by cancer, and we are also helping to train nurses and other professionals in having supportive conversations about work.
The first Macmillan clinical trials team

The first Macmillan clinical trials team

Cancer research studies (clinical trials) play an essential role in developing new approaches to managing disease and improving the effectiveness of existing treatments. Here at St Helens and Knowsley, we have seen an increase in study participation by promoting cancer research, particularly in areas that haven't previously been involved in research studies. The financial year 2015–16 enabled 152 patients diagnosed with cancer to participate in studies, and there are currently 17 open studies actively recruiting.

The cancer research team consists of two cancer research nurses and two cancer data managers. We work solely on cancer trials, covering up to 20 studies across eight tumour groups and two hospitals.

Becoming a Macmillan team

As a senior research nurse, I work alongside Macmillan clinical nurse specialists for each cancer tumour group. I was interested in the work that Macmillan do and after investigating further, I decided that, as cancer research studies and our team play an important part in people’s cancer journey, I would apply for the team to be adopted by Macmillan.

The team wanted to enhance the perspective that cancer research studies are part of the patient pathway and not a segregated aspect of patient care. This supports the NHS Cancer Reform Strategy (2007) and Achieving World-Class Cancer Outcomes (2015) policy guidance. Both highlight the importance of research environments in enabling new interventions that can significantly improve treatment outcomes.

Finding out, in August 2016, that we had been adopted by Macmillan was fantastic. It was a real honour to become the first cancer research team in the country to be given the Macmillan title, and for us a team to become Macmillan professionals.

Benefits of adoption

Being adopted by Macmillan has not changed what we do but it has helped to highlight the importance of our work. Patient, public and staff awareness of cancer research continues to grow. The benefits of being adopted by Macmillan have been clear, allowing the team to access information, support and education. The team and I feel that being part of Macmillan allows us to better support cancer patients, and we are fully committed to the organisation’s ethos and values.

This achievement has only been made possible by the continued support from the committed consultants who take the role of Chief and Principal Investigators, support services, and most importantly the patients who give up their time to take part in cancer research studies. We have an excellent relationship between teams, allowing us to carry out our studies safely and ethically, while keeping the care of those taking part as our priority.

Further Information

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St Helens and Knowsley Teaching Hospitals NHS Trust
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The role of a programme manager

How can a programme manager support a strategy? Amal Shandall describes her work as a Macmillan Palliative Care Service Improvement Lead.

The Gwent Palliative Care Strategy covers the five boroughs in the Gwent area of Wales: Newport, Torfaen, Blaenau Gwent, Caerphilly and Monmouthshire. The aim is to ensure that all patients with palliative care or end of life needs, along with their families and carers, receive a high-quality service that is safe, dignified, personal and respectful.

My role is programme manager for the eight workstreams of the strategy until June 2018. I have been implementing the strategy across Aneurin Bevan University Health Board and the partner organisations who helped develop the strategy before I took up post in June 2015. These partner organisations are Hospice of the Valleys and St David’s Hospice Care.

I provide programme management support and direction to all eight workstreams, and ensure the agreed deliverables and objectives are regularly recorded, monitored and achieved by set deadlines.

I also act as a conduit between the workstreams, to avoid duplication and ensure a more effective and efficient use of resources in implementing the strategy.

Achievements
To date, some of my actions in implementing the strategy have included the following:

• Developing a communication and engagement plan.
• Creating a ‘one-stop’ web page where contact details of everyone involved in the programme can be accessed quickly. The page can also be used to highlight achievements as the strategy is implemented.
• Launching a newsletter to increase awareness of and engagement with the Gwent Palliative Care Strategy. The newsletter is widely distributed to all health board staff, primary care teams, local authority staff, third sector organisations and care homes.
• Recruiting strategy representatives from teams including Frailty, Social Services, Divisional Nurses and the Nursing and Care Home Forum. The number of representatives has increased from approximately 50 to 150 people over the past few months.

Challenges and rewards
Being a Programme Manager means you need to be resilient, diplomatic, a good negotiator and highly organised. You must picture yourself in several roles – it can at times feel like you are a councillor a referee, a sales person, a public relations person, or even just a good listener. In my case, this is in addition to the main tasks of developing performance measures, updating the programme plan, producing eight highlight reports to monitor progress and producing annual and quarterly reports.

My name is Amal, which means ‘hope’, and I am a very optimistic person. I get to work with fantastic colleagues and enjoy the rush and buzz of the work I do, which I know is ultimately helping to improve palliative care for people with cancer and other health conditions.
Diabetes and cancer treatment

Richard Elworthy, Macmillan Expert Information Development Nurse, writes about a new booklet to support people undergoing cancer treatment while living with diabetes.

It’s estimated that as many as 1 in 5 people with cancer also have diabetes. According to the charity Diabetes UK, the number of people living with diabetes has more than doubled since 1996, with approximately 4.5 million people in the UK now affected by the condition. As cancer incidence also rises, it is likely that increasing numbers of people will be living with both conditions.

Diabetes and cancer risk
People with diabetes are at greater risk of developing certain types of cancer. We don’t know why this is, but it may be because type 2 diabetes has similar risk factors to several different cancers. For example, being overweight increases the risk of developing type 2 diabetes, but also cancers of the oesophagus, bowel, breast, womb and kidney. Both diabetes and cancer are also more common in people as they get older.

People with type 1 diabetes are at more risk of developing cancer of the stomach or cervix. Having type 2 diabetes increases your risk of cancer of the pancreas, womb, bowel, bladder, breast and liver.

Some people with cancer are also at risk of developing diabetes. You are at greater risk of developing both type 1 and type 2 diabetes if you have cancer of the pancreas, liver or bowel.

Managing two conditions
Having diabetes can complicate cancer management. Some scans and investigations commonly used to diagnose and monitor cancer need to be more carefully planned for people with diabetes. Investigations that require someone to be nil by mouth, as well as scans such as PET and those involving contrast medium, can all affect a person’s blood sugar.

Many of the treatments used in cancer care can adversely affect blood sugar levels. The most notorious perhaps is steroids, but other drug treatments, including chemotherapy, hormonal and targeted therapies can also have an effect. During and immediately after radiotherapy, blood sugar levels can rise, and can then drop. Being nil by mouth for surgery needs to be carefully managed and might involve infusions of glucose and insulin. A person with diabetes might be slower to heal than someone who doesn’t have diabetes, and at a greater risk of wound infection.

Coping with side effects
Perhaps the biggest issue for people with diabetes undergoing cancer treatments will be managing their blood sugar while coping with side effects. Common side effects of cancer treatment, such as nausea and vomiting, diarrhoea and fluctuations in appetite, can make it difficult to maintain target blood sugar levels. It is important to avoid dehydration, which can be a serious problem for people with diabetes. Being less active than normal, which is also common during cancer treatment, can also affect blood sugar levels for some people.

Macmillan, in partnership with Diabetes UK, has produced a booklet for people with cancer and diabetes. It contains plenty of tips to help people with diabetes cope with cancer treatment side effects. People are encouraged to plan ahead and seek advice from their diabetes team before...
starting treatment. Where possible people should stick to their normal routine and diet. However, this may not always be achievable. They may need to monitor their blood sugars more frequently and, depending on how they are affected by the cancer treatment, they may need to adjust their regular medication.

Advanced cancer and diabetes
Trying to manage diabetes effectively can be complicated for someone with advanced cancer. There may be a range of symptoms that can make it difficult to control blood sugar levels. This includes symptoms such as loss of appetite, nausea, fatigue and constipation or diarrhoea.

As people become more unwell, controlling their blood sugar becomes less important. However, having very low or high blood sugar levels can cause unpleasant symptoms, and should be avoided. Towards the end of life there should be no restriction on what someone with diabetes can eat. They won’t need to monitor their blood sugar level as often and can gradually reduce doses of insulin or other diabetes medications. The diabetes team will be able to help with this.

Further information
Our new booklet explains how cancer treatments can affect diabetes and make it difficult to control blood sugar.

It features Clare’s story through quotes and photographs. Clare was diagnosed with type 2 diabetes just before she received her cancer diagnosis.

Diabetes UK is the UK’s leading diabetes charity. They provide information, advice and peer support, so people with diabetes can manage their condition effectively. Visit diabetes.org.uk for more information.
Improving brain tumour and CNS pathways

Helen Sowden talks about the first Macmillan transformational change programme for a complex and rare cancer.

A new flagship programme in the Humber Coast and Vale Sustainable Transformation Plan area, centred in Hull Royal Infirmary and Castle Hill Hospitals, aims to optimise the experience and quality of life for people affected by brain tumour or central nervous system cancer (CNS). Working across the pathway from early diagnosis to palliative and end of life care, this will be achieved through improving consistency and equality of access to support and services required to meet holistic needs; and a patient pathway that identifies and addresses holistic needs and delivers the right level, type and intensity of support.

Complex needs

Patients affected by brain or CNS tumours can encounter numerous issues due to the disease or as a consequence of treatment. Health and social care issues can be complex and include physical, psychological, social and emotional concerns for both patients and carers. Describing the impact of this cancer was a challenge for the programme team. A series of short films were commissioned, where patients and carers describe the changes they have experienced. These highlighted and celebrated the work carried out by the multi-disciplinary team and summarised what the programme is wishing to achieve. Go to tinyurl.com/yb6k404q to watch the ‘Programme’s Story’ film.

Patient feedback revealed that people want: ‘time to ask questions and have honest conversations’, ‘one point of contact for the answers’ and ‘that one phone call that can help you sleep at night.’

To gain detailed insight into the patient and carer experience before, during and after treatment, various pieces of work took place to capture in-depth understanding. An example was a facilitated illustrative session with patients where an illustrator took sketches of the discussions taking place.

Neuro oncology care coordinator

Pathway mapping took place with the clinical teams to understand potential opportunities for service improvement. This identified that a role to support the clinical nurse specialists (CNS) and patients would be of value. Time was spent with patients and the CNS team to understand what would be expected from a supportive post. To provide clarity on role expectations, boundaries and potential learning and development requirements, a competency framework was developed to support the role and service. Patients were involved in the development of the job description and patient interview panel for the role. This role developed into a neuro-oncology care coordinator, working alongside the clinical nurse specialists. The postholder has been in role since June 2016 and has made an immediate difference to the team.

Louise Baker, Macmillan Neuro Oncology Clinical Nurse Specialist, said: ‘The role has surpassed expectations in terms of the impact it has on the service and benefit for patients and carers. We feel we’re able to offer a better service to patients now.’

A recent evaluation of activity data for the neuro oncology care coordinator role showed that 65%...
of the postholder’s time was spent in direct contact with patients or dealing with their queries, which includes liaising with other healthcare professionals and following up appointment dates.

Work is currently taking place with patients and carers to gather feedback on the impact the role is having on their experience.

Next steps
The next phase of the programme is focusing on elements of the Recovery Package, Holistic Needs Assessments, risk stratification and opportunities to link to local living with and beyond cancer teams. Further exploration of patients’ and carers’ experiences of the palliative and end of life care part of the pathway has recently been completed, with interviews taking place with both patients and carers. It is hoped that this enriched insight will support activities to enhance what currently works and what might need improving.

The programme is now part of the priorities of the Sustainable Transformation Plans, within the Cancer Alliance. This will support the sustainability of work streams once the improvement programme ceases in July 2018.

The success of the programme has been to dedicate time to gather a detailed understanding of the service experience from patient, carer and expert clinical team perspectives. The heart of service improvement has been led from those who know best. This has taken dedicated time, partly due to the complex nature of brain tumour and CNS cancer.

‘We hope to be able to share the learning with other complex and rare cancer pathways and to other brain and CNS pathways across the UK,’ says Lorraine McDonald, Partnership Manager. ‘Being able to share learnings based on the lived experience of patients and carers is such rich and valuable insight for improving the experience of people living with cancer.’

Further Information
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A sketch by illustrator Graham Ogilvie of discussions between patients and carers provides an alternative approach to help people whose cognitive approach has been affected by a brain tumour or CNS to explain their experiences.
Introducing cancer rehabilitation leads

Charlotte Brooks and Tom Cave are working in innovative new roles as Macmillan cancer rehabilitation leads.

Charlotte’s story
I am an occupational therapist and recently completed a PhD in health literacy. I began working as a Macmillan allied health professional (AHP) cancer rehabilitation lead and teaching fellow in October 2016. This clinical academic role is a collaboration between University Hospitals Southampton (UHS) and the University of Southampton.

At UHS, my aim is to develop cancer rehabilitation and survivorship services. Working together with people with cancer and staff, I am exploring where there is potential for increased AHP input in the patient pathway, with a particular focus on occupational therapists, physiotherapists, dietitians and speech and language therapists. One of my projects is focusing on designing, implementing and evaluating AHP input at an outpatient palliative radiotherapy clinic where there is currently no AHP input. Cancer specialist AHPs often provide care to patients after admission to a hospital or hospice. The proposed model aims for earlier and preventive interventions to support people to self-manage and have an increased quality of life. I am also exploring how AHPs could contribute more within the head and neck cancer pathway and evaluating how well UHS cancer services meet patients’ health literacy needs.

At the university, my aim is to evaluate how prepared students feel to work with people who have cancer and how well cancer rehabilitation and survivorship ideas are embedded within the Faculty of Health Sciences curricula. After this, I will implement changes as required. I would like to see students entering clinical practice feeling fully prepared to support people to self-manage and live with and beyond cancer.

I am excited to see these projects progress and evolve. These innovative posts offer huge potential to change practice in ways that benefit people with cancer.

Tom’s story
I am a physiotherapist and have worked across England in various NHS Trusts treating patients in acute inpatient wards and outpatient musculoskeletal departments. I started in my role as the University Hospitals Bristol NHS Foundation Trust (UHB) Macmillan Allied Health Professions Cancer Rehabilitation Project Lead in July 2016.

This two-year, Macmillan-funded project aims to establish what AHP services cancer patients access at UHB, and to explore whether there are any areas of unmet need. From the scoping process so far, we have identified three key areas to focus on: fatigue management, ‘prehabilitation’ and access to therapy during treatment.

We have developed pilot programmes to address these areas, with a Cancer Related Fatigue Management Programme, a Therapy Treatment Support Service and a Prehabilitation Support Programme all in action. With these programmes, we hope to improve patient experience and help people cope with the realities of living with and beyond cancer.

It’s excellent to network with fellow Macmillan Professionals like Charlotte to share experiences and good practice and develop new ways of working to improve outcomes for patients. By listening to patients’ experiences and using our AHP knowledge, we can identify what works well and create sustainable and cost-effective change that delivers the best services for those living with and beyond cancer.

Further information

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In focus: Mental health and cancer

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Cognitive rehabilitation after cancer treatment

Natalie Rooney talks about lessons learned from a pilot memory group programme in NHS Greater Glasgow and Clyde.

The term ‘chemobrain’ was first coined by women with breast cancer in the 1980s, but it is only within the past decade that it has been systematically investigated within psychological outcomes research literature. Cancer-related cognitive changes (CRCC) refer to a range of cognitive deficits that are frequently reported by cancer survivors, including difficulties with memory, attention, concentration and executive functioning (i.e. planning, organisation and problem solving). It is not certain how many people experience these memory and concentration changes as a result of cancer treatment. Prevalence rates vary widely in studies, ranging between 13–78% with around 35% of people presenting with moderate to severe difficulties. The specific neuro-biological mechanisms are unknown. Research suggests that there may be a number of factors that contribute to the condition, including chemotherapy; other cancer treatments; anxiety, fatigue, depression; and changes in cytokines (Figure 1).

The adverse impact of CRCC is far-ranging. People often comment about the wide-ranging impact of cognitive difficulties, affecting home life and relationships as well as employment.

Emotional adjustment
We have been running our memory group programme since April 2016 under the Transforming Care After Treatment (TCAT) programme, which is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities to support a redesign of care following active treatment of cancer. Utilising funds for two years, we are trialling a five-week group psycho-education programme to enable cancer survivors to understand and manage their memory and concentration changes after treatment.

The TCAT five-week programme consists of an introductory session; three specific sessions on attention; short-term memory and executive functioning (planning

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Figure 1. Pine Street Foundation, Becoming Your Own Advocate Newsletter, 2005.
Mental health In focus

and organisational skills); and a summary session that is open to family and friends of participants. The programme is open to individuals of all cancer diagnoses and there is no specific cut-off for time after active treatment. The sessions have been received well and appear to support peoples’ emotional adjustment after treatment.

Outcome measures used to assess the effectiveness of the programme have been the quality of life measure specifically for cognitive functioning (FACT-Cog) and the PHQ-9 and GAD-7 to assess psychological functioning. Initial analysis indicates a reduction in distress levels associated with cognitive changes.

Feedback
Group participants have reported that the programme helps them to understand and better manage cognitive changes after treatment:

The biggest plus – I’m not going insane.' 48 year old male, Hodgkin’s Lymphoma

'I feel more confident that I can remember, that beforehand I was doing the right things by using brain training apps. And hearing about the theory, as well as seeing others with the same symptoms, helped me progress.' 20 year old female, Osteosarcoma

Group participants called for a greater awareness of CRCC among health and social care professionals across all sectors. To this end, we ran an education event chaired by our project’s lay representative and incorporating sessions by former group participants who spoke about the challenges of living with and adapting to CRCC. Professor Robert Ferguson, who has developed a memory and attention adaptation (MAAT) training programme was the plenary speaker.

Jess’s story
Jess vividly recalls sailing through her first episode of breast cancer while she was a young mother. However, when she was diagnosed with breast cancer for the second time in her 60s, she was floored by the treatment and it took her far longer to regain her strength afterwards. As part of her Holistic Needs Assessment (HNA), carried out by the Improving Cancer Journey team, Jess was asked whether she experienced any memory or concentration difficulties. This immediately sparked off a flurry of concerns about feeling mentally sluggish and struggling to keep up the pace of day-to-day tasks.

'It got to the stage where I stopped meeting up with friends because I couldn’t keep up with the conversation. Somebody would say something and my mind went totally blank. I had no idea what they were talking about and yet I had been involved, or what I thought was being involved, in the conversation.' Jess

The memory group programme run under the TCAT programme was suggested as a potential means of support.

Jess did come along to one of the group programmes and tried out the various cognitive compensation strategies, which she found helpful. Coupled with the understanding that this can be a common problem following treatment, she reported being better able to manage.

Jess volunteered to be filmed on our educational video, which serves as an invaluable resource highlighting some of the challenges of living with CRCC post treatment as well as some of the ways of managing it. The CRCC video can be found on the NHS GGC YouTube channel.

Further information
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Macmillan Mental Health and Cancer Taskforce

Catriona Burns talks about the work of the Macmillan Mental Health and Cancer Taskforce.

A mental health problem is the most common co-morbidity experienced by people living with cancer, and depending on the type of condition(s), people with mental health problems can be 30–74% more likely to die from cancer than the overall population of people diagnosed with cancer. In addition, people living with cancer often struggle to access appropriate mental health assessment and treatment; and people living with mental health problems can have their cancer symptoms overlooked, with their physical symptoms being seen as part of their mental health problem.

A user-led network

Established in 2015, Macmillan’s Mental Health and Cancer Taskforce (MHTF) was a user-led network of people living with and beyond cancer, carers, friends, relatives, health professionals and Macmillan staff. Led by a reference group of eight taskforce members, the goal from the outset was to better understand and tackle the inequalities faced by people living with, or affected by cancer and mental health problems.

Issues identified

Some of the main issues facing people with both cancer and mental health problems identified through surveys and engagement events include:

- Mental health is harder to talk about compared to cancer (attached stigma, taboos, lack of awareness).
- People have to fight for appropriate treatment (for both cancer and mental health conditions, sometimes falling between services).
- Training is needed for professionals to help prevent diagnostic overshadowing or concerns being dismissed without due consideration.
- Isolation.
- Masking difficult feelings to protect others, avoiding unhelpful responses or upsetting themselves.
- Employment issues.
- Lack of information and support (lack of support for mental health problems, language, cultural or social barriers).

Suggested solutions from the MHTF include:

- Improve local information and signposting resources for mental health support, including online.
- Make psychological support available on wards and in clinics.
- Humanise cancer care to reduce the need for specialist psychological support.
- Implement the eHNA reliably at appropriate stages, and link into signposting resources.
- Support healthcare professionals through awareness raising, training, community of practice.
- Employment support through campaigning, training and resources.
- Provide carer support, including online peer mentoring, forums and training.
- Peer support through groups, 1:1 trained peer support and mentoring.

Health professionals

The taskforce also sought to gain further insight into Macmillan professionals’ experiences of mental health and cancer through a survey distributed both online and at the...
Macmillan Professionals Conference. There was a total of 141 responses, with job roles ranging from project officers to allied health professionals, educational leads, nurses, GPs and more. Results included information on:

- Obstacles facing professionals, including time constraints, a lack of confidence, inadequate suitable environments, poor communication and a lack of resources or conflicting priority of focus (e.g. the emphasis on the physical aspects prioritised).
- The difference in health professionals’ confidence levels when asked about treating and supporting people with mental health problems in general (‘a little’ to ‘quite’ confident), and specifically those with pre-existing conditions (‘quite a bit less confident’ to ‘about the same’).
- Lack of confidence related to concerns over worsening a person’s condition and not understanding different cultural and religious beliefs.

The majority (94.7%) of Macmillan professionals surveyed stated they would benefit from further mental health training with face-to-face approaches preferred over online learning (but with a combined approach being recognised as best). Macmillan professionals also articulated a desire to see assumptions challenged, increases to the depth and breadth of understanding of the dual impact cancer and mental health have on one another and greater involvement by existing Macmillan teams (the Therapy and Physical Activity Teams were named specifically). The desire for further training was reiterated in a more recent survey of therapists, counsellors and psychologists (73%), which followed on from the article, ‘Counselling people with cancer’.

References
Cancer and pre-existing mental health conditions

John was diagnosed with prostate cancer in 2012 and feels there is little support for people with pre-existing mental health conditions.

I first recall having depressed and suicidal thoughts when I was about eight years old and was diagnosed with depression at 13. In 2003, I was diagnosed with rapid cycling bi-polar affective disorder. Since then, I have also been diagnosed with severe depression, severe anxiety, obsessive compulsive disorder, an undefined personality disorder and ‘traits of emotional instability’. It seems that every mental health professional takes a different view.

I also have numerous physical problems including cardiovascular disease, asthma, hemiplegic migraines and osteoarthritis. This means that it can be very difficult to tell what is affecting me on any particular day.

Daily life
Most days I tend to feel low or depressed. However, it can be very difficult for others to see this as I have trained myself to ‘present well’. When I feel this way, I tend to isolate myself. I made two serious attempts to take my own life in 2015, both of which led to stays in hospital. The best way to deal with suicidal thoughts is to talk to someone, and I have built good support structures around me to allow this to happen.

When my mood goes high, I must be even more careful as I think I’m invincible, go on spending sprees and become everybody’s friend. When I feel my mood becoming this way I tell someone, usually either my best friend, mental health nurse or social worker.

After years of trying different things, I am now mostly stable, taking one medication for my mental health and getting as much exercise as I can. Being outdoors is very important to me, which conflicts with the way I isolate myself – that’s bi-polar!

Cancer diagnosis
My father had terminal prostate cancer. When I asked if I could have a blood test, my GP agreed and less than a month later I was diagnosed with prostate cancer. My appointments with the oncologist and urologist each lasted about 10 minutes as I knew everything from conversations with my father and had done research. I took maybe two minutes to agree to active monitoring with my urologist. Since the diagnosis, I have seen my urologist twice and not seen an oncologist again.

Impact on mental health
The cancer diagnosis has sometimes had a serious impact on my mental health. When I have tried to get help in dealing with mood swings it has always been dealt with as a mental health problem and not a problem in dealing with the cancer, which is then subsequently affecting my mental health. This means that I have felt isolated and have had to cope by myself. I have not had support from any professional in my oncology or urology team when I have become depressed due to having cancer.

For example, when I went to the cancer support and information centre at the hospital I had just been to a non-cancer appointment, but was feeling depressed about the cancer. I thought I’d go to the centre to have a chat with someone and get some support. I spoke to the person at reception and when I mentioned that I have mental health problems she suggested that I see my
Callie was diagnosed with breast cancer in 2011 and has found art therapy enormously helpful in coping with depression and anxiety.

Nearly 27 years ago, I had post-natal depression that was not picked up until my son was two. This was treated unsuccessfully on and off and never resolved. When I was diagnosed with triple negative breast cancer in 2011, one of the nurses told me, ‘You mustn’t ever come in here looking unhappy – I want to see you smiling’. I was one of those girls who did what she was told and put up my shield.

After treatment, I attended a support group where someone talked about their friend who had died from secondary cancer and it hit me. I rang up my doctor and said, ‘I need help’. I was treated for severe depression using medication. I found out about an oncology counsellor by chance and had a course of counselling, but there were many more underlying issues and no one quite knew what to do with me. This has been my story: if you don’t fit into a box, you really struggle because you get pushed from pillar to post.

Art-therapy techniques have made an enormous difference. They are often seen as frivolous, but art makes you forget yourself and express what’s going on in your body. I now coach other people in doodling, collages, dream boards and journaling. This also prevents me from feeling so lonely when working from home. Loneliness has been by far the biggest factor in my mental health. Throughout my depression, I have tended to hide myself away – retreat into my shell. This is a hard habit to break even now.

For someone with a pre-existing mental health condition, I think it is incredibly important that there’s more liaison between the GP and the healthcare team. My history of depression was not picked up at diagnosis. I’ve found that holistic needs assessments can sometimes be treated as a tick-box exercise, but when done thoroughly, they can save a lot of work later on and a lot of money spent on pharmaceutical drugs.

I wish someone had said: You will have days when you don’t want to get up and do anything. Don’t worry – you’re normal. Everybody feels like that. Stay in touch with the people who are caring for you. Everyone needs a cheerleader.
A practical guide to living with and after cancer

Eating problems and cancer
MAC13613
3rd edition
This booklet highlights some common eating difficulties, why they happen, and suggests some practical ways to manage them.

Giving up smoking
MAC12514
4th edition
A booklet looking at the changes you may want to make to your lifestyle after cancer treatment. It explains the benefits of giving up smoking and has practical advice about how to stop smoking and 'stay stopped'.

Life after cancer treatment
MAC11661
8th edition
A booklet about the emotional and practical issues you may face after cancer treatment. Covers a wide range of issues from feelings, relationships and lifestyle choices to follow-up after treatment and physical changes.

The building-up diet
MAC13614
3rd edition
This booklet has suggestions on how to help boost your energy and protein intake when your appetite is poor. There are sample menus, and a suggested shopping list of items that may help when preparing meals.

Understanding Hodgkin lymphoma
MAC11628
11th edition
A booklet explaining Hodgkin lymphoma, covering the causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

Understanding non-Hodgkin lymphoma
MAC11635
15th edition
A booklet explaining non-Hodgkin lymphoma, covering the causes and symptoms, diagnosis, staging and grading, treatments and clinical trials. It also talks about emotional, practical and financial issues.

Crossword

Clues across
1 Mixed-breed dog
5 Domesticated
7 To badger continually
8 In disfavour or the kennel?
9 Roads and tracks
10 Munch gum
13 Decorative fabric made in Nottingham
14 Tilt to one side
18 Choose
19 Just the ticket
21 Over-tanned
22 A bundle of notes
23 Lose volume or brightness
24 Wandered off and got lost

Clues down
1 Business with total market control
2 A drink before bed
3 Pungent red salad plant
4 A gift left by will
5 Gardener's hand tool
6 Fine spray of liquid
11 River or canal
12 Private and off the beaten track
15 Quick and agile
16 Kilts or tutus
17 Type of ale
20 Cougar