Sharing good practice

PERSONALISED CARE

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Putting personalised care at the heart of cancer support

Clare Woodford, Macmillan Senior Policy Adviser, outlines Macmillan's vision for delivering personalised cancer care.

At present, coronavirus (COVID-19) has abruptly become the main NHS priority and budgets and staff for cancer care are stretched to capacity. In these difficult times, it may sound fanciful to discuss personalised care. If there is a struggle to meet the 62-day waiting time target for treatment, it may seem less urgent to think about tailoring care around the individual.

Yet, personalised care describes a philosophy that is integral to high-quality cancer services. In essence, Macmillan understands personalised care as being 'designed in collaboration with the person who needs it, or with someone who knows them well, so that it is tailored to meet individual needs'[1]. Macmillan's approach has always embodied these principles.

Macmillan's approach

Personalised care is a crucial part of what Macmillan professionals do. Programmes such as Improving the Cancer Journey and Transforming Cancer Care (both in Scotland), and of course the Recovery Package, put people living with cancer at the centre and build support around them. This approach:

- achieves a better service for people with cancer
- uses our workforce more effectively
- can save money by reducing hospital stays and treating people closer to home.

Our training, toolkits and guidance help Macmillan professionals to build their skills in personalised care.

Delivering our agenda

There are important opportunities to deliver Macmillan's agenda for personalised care across the health and care system.

Last year's NHS Long Term Plan for England committed that every person diagnosed with cancer would have access to personalised care by 2021[2]. This includes needs assessment, a care plan and health and wellbeing information and support. The Universal Personalised Care model outlines a blueprint for achieving this goal, including training 75,000 professionals in personalised care and support planning by 2023/24[3]. The new 'Personalised Stratified Follow-up' approach sets out a clear programme to tailor pathways for people with breast, colorectal and prostate cancers around their individual needs[4].

Scotland and Wales have national commitments for personalising follow-up care[5] and delivering electronic holistic needs assessments[6] respectively. Northern Ireland's new cancer strategy is also expected to prioritise person-centred care[7].

We are determined that these policy opportunities should make a meaningful difference to everyone with cancer. However, as Macmillan professionals

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know only too well, there is a big difference between a glossy government strategy and a fully funded, staffed service.

Key challenges

Major challenges persist in recruiting, retaining and deploying the cancer workforce in health and social care services. Our 2019 'Voices from the Frontline' report showed that 'overwhelming' caseloads and dwindling access to continuing professional development are hindering clinical nurse specialists from delivering personalised care[8].

Macmillan intends to scrutinise people's needs at different stages of the cancer pathway and whether those needs are being met. While people still identify unmet needs, the system is not truly personalising their care.

Almost 3 million people are now living with cancer[9] and at least one in four of those are estimated to be facing poor health or disability after their treatment[10]. The need for support does not stop when treatment ends.

Time for change

It is time for system leaders to think differently about designing and commissioning cancer services. This should be in line with national policies calling for a more personalised approach. There is an opportunity for the health and care system to work together in a truly joined up way, including with the voluntary sector and community partners. This issue of Sharing good practice highlights just some of the numerous examples across the UK of a coordinated approach to delivering care (all articles were submitted prior to the coronavirus outbreak and may not reflect the impact on services).

Macmillan is currently undertaking research into what changes are needed to the health and care system to deliver personalised care. We are producing a report later this year, which will aim to influence national, regional and local policymakers.

It is our job as Macmillan policy professionals, working with you the cancer experts, to hold UK governments to account on their promises. We must demand that the best care is available for everyone with cancer, whatever they need and wherever they live.

If you are interested in contributing to our research on integrated cancer services, please get in touch with me at **cwoodford@macmillan.org.uk.**

Personalised cancer care in South West London

Dr Owen Carter, Macmillan GP, and Janice Minter, Macmillan Lead Cancer Nurse, explain how person-centred care is delivered across the borough of Wandsworth.

Dr Owen Carter on primary care services

I believe passionately that primary care services are integral in helping to deliver personalised cancer care. Primary care teams are expert in providing holistic, joined-up care and recognising what matters to an individual living with cancer. What can be problematic is finding time to identify and address these needs, and having a primary care workforce that feels skilled in dealing with any issues raised.

For the last three years at Wandsworth Clinical Commissioning Group in South West London, we have used a Holistic Cancer Care Review. A GP or trained practice nurse carries out this review nine to 12 months after an initial diagnosis of cancer. This is in addition to the Quality and Outcomes Framework (QOF) Cancer Care Review, which takes place three to six months after diagnosis.

In my role as Macmillan GP for Wandsworth, I have encouraged GPs and practice nurses to use:

- the Macmillan Cancer Care Review template when carrying out the QOF Cancer Care Review
- a bespoke computer template when undertaking the Holistic Cancer Care Review.

The bespoke template includes details of local services, such as the Wandsworth Macmillan Move More programme and St. George's Hospital Macmillan Cancer Psychological Support Service.

We are now upskilling our Primary Care Network social prescribers. Macmillan training will empower this new primary care workforce to identify issues faced by people with cancer and signpost them to relevant services.

Our work is further supported by the Wandsworth Macmillan primary care navigation pilot. Skilled navigators undertake an electronic holistic needs assessment (eHNA) and develop a shared care plan with each individual. This work links the needs of people who have cancer with services that can help.

Finally, we are building on the great work of Sandra Dyer, Macmillan Primary Care Lead Nurse, and the Macmillan Primary Care Nursing Programme for South West London. The aims of this programme are to:

- upskill the primary care nursing workforce
- give practice nurses the skills and confidence to carry out cancer care reviews
- help practice nurses gain greater confidence in seeing people with cancer.

These initiatives within primary care are helping to improve the delivery of personalised care for people affected by cancer.

Janice Minter on secondary care services

As the Macmillan Lead Cancer Nurse at St. George's University Hospitals NHS Foundation Trust, my key priorities include:

- professionally supporting the cancer nursing workforce
- improving the patient experience for people living with cancer.

If we deliver personalised care to people living with cancer, I strongly believe that this will improve their patient experience.

One of my main duties is to ensure that every person diagnosed with cancer is offered a supportive conversation with a clinical nurse specialist (CNS). This conversation is aided by a Macmillan eHNA and care plan, which allow us to identify people's needs and plan appropriate support.

Following a successful pilot, I am proud to say that we have 10 Macmillan support workers at the trust. As every CNS now has access to a Macmillan support worker, their direct care time has increased. The Macmillan support workers liaise closely with primary care navigators in Wandsworth to improve the transition between primary and secondary care.

Our Macmillan Information and Support Centre is the hub for people with cancer and staff at the trust. The centre coordinates health and wellbeing events, which cover both generic and tumour-specific topics to provide the information resources that people need. The Macmillan support workers ensure that people with cancer are invited to these events.

Ensuring that all people living with cancer have access to personalised care remains a challenge for the cancer workforce. It is often seen as an extra task rather than a core duty. We have therefore recently developed a new role for a lead CNS focusing on personalised care. The aim of this post, which has been funded by Macmillan for two years, is to embed personalised care within the cancer workforce. This role will help raise awareness of personalised care across the whole organisation and design IT solutions for end of treatment summaries.

In my role I work closely with Macmillan GPs, particularly Dr Owen Carter. When developing services, we try to ensure that they meet the needs of both primary and secondary care. Our goal is to provide the support and skills required to achieve personalised care for people living with cancer.

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Cancer care closer to home

Lana Davidson, Macmillan Transformation Manager, and Ros Haynes, Macmillan User Involvement Facilitator, outline a project to redesign local cancer services.

Mid Cheshire Hospitals NHS Foundation Trust serves a population of about 300,000 people[11] across five care communities. Cancer affects many people in Central Cheshire, with more than 1,100 new cancers in South Cheshire and more than 600 cancers in Vale Royal diagnosed each year[12]. New cancer diagnosis rates are higher than the average for England (over 5% higher in South Cheshire and nearly 7% higher in Vale Royal)[12].

Cancer pathways for people who have a suspected or confirmed cancer diagnosis within South Cheshire and Vale Royal spread geographically in three directions. These pathways also cover three different cancer alliances.

Many people living in South Cheshire and Vale Royal travel long distances due to the complex pathways for treatment. The Macmillan closer to home project was created to address this issue and deliver more personalised cancer care in the local community. Personalised care is a key element of the NHS Long Term Plan. It means people having choice and control over the way that their care is planned and delivered.

Gathering feedback

The project scoped the redesign of local cancer services to identify options for treatment closer to home. Over 18 months, the views of more than 500 people in local towns and villages around Cheshire were collected. Some people had to travel over 80 miles for treatment or blood tests.

A Macmillan Transformation Manager worked with clinicians and staff to calculate the numbers of people who could potentially receive treatment in the local area.

To assist in gathering people's views, a User Involvement Facilitator set up a Patient and Partner Experience Group. Members of this group had undergone cancer treatment and provided valuable insight, together with their families and carers. They wanted to use their experiences to help others, and shared feedback to influence the redesign of services.

More than 60 events were held throughout the area to talk about the project. We also spoke to hospital staff and health staff in the community. Everyone was in favour of offering cancer treatments more locally, where appropriate.

Need for personalised care

Staff and people with cancer felt that there should be a choice about where to have treatment, which is an important aspect of personalised care.

Travel had a big impact on people living with cancer, in terms of time, cost and anxiety. In some cases, family members had to use annual leave to accompany people to appointments.

We received 179 comments in the South Cheshire and Vale Royal area. The main themes included:

- **Blood tests:** People with cancer, their families, hospital and community staff wanted blood tests to be available locally. This would avoid people having to travel to the Christie Hospital in Manchester or the place where they were having treatment.

- **Treatment line service:** There were not enough trained hospital staff (particularly in the accident and emergency department) to support people fitted with PICC lines or portacaths.
- **Parking:** Concerns were voiced about the cost and limited availability of parking spaces on the hospital site.

The development of Integrated Care Partnerships in Cheshire East, and Cheshire West and Chester, is intended to provide more community-based services. This aligns with the aims and objectives of our Macmillan-funded project.

Acting on feedback

Based on the feedback received, we produced a business case for the trust's board to consider and improve local cancer services. During 2020, changes will be phased in so that more people can receive treatment locally at the trust or St. Luke's Hospice in Winsford. This is likely to be a more convenient option than travelling to the main Christie Hospital site in Manchester.

In April a change to IT systems meant that blood tests could, for the first time, be carried out locally at the trust and sent to the Christie Hospital. Parking spaces will increase, and in late summer, dedicated parking will be introduced outside the Macmillan unit for people having chemotherapy. Extra line (PICC and portacath) management training will also be organised for staff locally to support people who have lines fitted.

It is hoped that these changes will help to deliver personalised cancer care closer to home.

For more information or to see the full report about this project, please contact **josmith@macmillan.org.uk**

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Measuring and improving person-centred care

Professor Tanya McCance, Mona Grey Professor of Nursing Research and Development at Ulster University and Dr Brighide Lynch, Macmillan Project Coordinator, on co-producing and implementing person-centred key performance indicators in cancer nursing.

Following a successful Macmillan pilot project in the chemotherapy unit at the Ulster Hospital, Macmillan hosted an engagement workshop in October 2017. The aim was to explore the potential of co-producing a person-centred cancer nursing implementation study across chemotherapy units in Northern Ireland.

This workshop included people affected by cancer, nurses from chemotherapy units in each of the five Health and Social Care Trusts, lead cancer nurses/managers and cancer service improvement leads. It inspired a shared vision and enthusiasm for a regional study across the chemotherapy units, focused on developing person-centred practice within the field of cancer nursing.

The Ulster University successfully applied for Macmillan funding to recruit a project coordinator to work alongside Professor Tanya McCance to undertake a larger scale implementation study. This began in March 2018 and ended in December 2019. The aim of the study was to explore the impact of using person-centred nursing key performance indicators (KPIs) to support the development of person-centred practice across ambulatory chemotherapy units.

The eight person-centred nursing KPIs:

KPI 1: Consistent delivery of nursing care against identified need

KPI 2: Patient's confidence in the knowledge and skills of the nurse

KPI 3: Patient's sense of safety whilst under the care of the nurse

KPI 4: Patient involvement in decisions made about his/her nursing care

KPI 5: Time spent by nurses with the patient

KPI 6: Respect from the nurse for patient's preference and choice

KPI 7: Nurse's support for patients to care for themselves where appropriate

KPI 8: Nurse's understanding of what is important to the patient and their family

The CIP-CAN project (Co-producing and Implementing Person-centred Key Performance Indicators in Cancer Nursing) builds on outcomes from a longstanding programme of research by Professor McCance and colleagues. Over a number of years, the team have developed eight KPIs (see green box) to assess the quality of nursing.

A set of tools were also developed to collect data that nursing teams could use to explore and improve the experience of care for patients and their families. The tools comprise patient surveys, patient stories, observations of practice and patient record reviews combined with staff interviews.

The outcomes from the research to date have highlighted that nurses at all levels value the information generated from using the KPIs. This is because it focuses on aspects of being person-centred, and there is a desire to support this work into the future.

The work has increased its reach through the development of the iMPAKT app. This offers a technological solution to support staff in collecting patient experience data, which enables real-time/near-time reporting.

The underpinning philosophy of CIP-CAN is grounded in collaborative and engaged ways of working, reflected in the use of a model for co-production. The Macmillan funding allowed each trust to recruit a local nurse champion, who worked closely with the project team, and the purchase of hand-held devises for data collection. The main role of the champion was to promote the project and ensure that all nurse colleagues in their chemotherapy unit were engaged.

People affected by cancer (peer facilitators) were also recruited as part of the local project team and took part in all aspects of the project, but particularly a lead role in data collection using the iMPAKT app. The peer facilitators focused on collecting patient stories and were supported by the local champions in each of the six sites.

Following three cycles of data collection, the team in each chemotherapy unit reviewed the results from each cycle and generated action plans to celebrate improvements and change practice.

In order to maximise sustainability, the development of knowledge and skills within the chemotherapy team was paramount. The project included several workshops to support practice development knowledge, covering topics such as working with different sources of evidence, clarifying values and beliefs and gaining knowledge of self and critical reflection.

Findings
Several emerging themes were identified from project evaluation:

- **Impact of the peer facilitators' role** – people with a lived experience of cancer are instrumental in creating meaningful engagement with patients, helping them feel at ease in sharing their views about their experience of care.
- **Value of local champions** – nurse champions were pivotal in supporting engagement, reflection and development of initiatives to improve person-centred practice.
- **Living out the principles of co-production** – the project demonstrates innovation through genuine co-production and collective leadership with people affected by cancer, clinical nursing teams, cancer service improvement leads, managers and academic experts.

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- **Celebrating good practice and boosting team morale** – using the iMPAKT app to enable real/near-time reporting was key to informing practice improvement, evidencing team performance in providing a good care experience for patients and encouraging teams to celebrate achievements, boosting team morale.

- **Shaping practice and service changes** – the project demonstrated that the data generated by the KPIs were improving practice within cancer nursing. One example is a regional change in the electronic record developed for use within chemotherapy units to improve nurses' understanding of what is important to patients and families (KPI 8).

Conclusion

The evidence generated by the use of the KPIs offers chemotherapy teams an opportunity to celebrate the delivery of high-quality care. The nature of the data generated reflects the patient voice, and offers valuable feedback to nurses that can inform the development of person-centred cultures in cancer nursing. The CIP-CAN study provides strong evidence of the value of implementing these person-centred KPIs using a model of co-production, and creates a firm foundation for wider implementation in future.

Macmillan Partnership Manager Lorna Nevin and Macmillan Engagement Lead Maura McClean on supporting the project.

Person-centred care is a fundamental cornerstone of how we support people living with cancer. However, it can be a challenge to capture and demonstrate the importance of this core element of care.

Macmillan is proud to be collaborating with Professor McCance, Dr Lynch and all our partners to bring this work to the heart of cancer nursing care in Northern Ireland. The CIP-CAN study demonstrates the positive and unique contribution of nursing across a range of settings. Added to this, the co- production approach taken throughout this work exemplifies how people affected by cancer have been meaningfully involved in shaping and informing the services they use and improving the experience for others.

From the outset, this initiative embeds the theoretical framework of person-centred care as well as the principles of co-production and practice development, enabling a positive culture of influence.

Empathy, understanding and mutual experience are the unique attributes that have contributed to the co-production aspect of this project. We witnessed the courage to ensure authentic co-production when ethical questions arose regarding the skills and resilience of people affected by cancer listening to the experiences of their peers. This concern was robustly addressed as each peer facilitator received training and had a support network around them, including the Macmillan Project Coordinator, the nurse champions and the Macmillan Engagement Lead.

Reflections on the importance of personalised cancer care

Liz O’Riordan, retired Consultant Oncoplastic Breast Surgeon, shares insights into providing personalised care based on her own breast cancer experience.

As healthcare professionals, we pride ourselves on providing high-quality care with safe, effective treatments. An equally important aspect of quality is patient experience. We need to tailor healthcare to the needs of each person, based on what matters to them and their individual strengths and needs.

The NHS Long Term Plan calls for every person diagnosed with cancer to have access to personalised care by 2021. This aim of taking a person-centred approach to cancer care has been repeatedly recognised in national policies and strategies. Yet, it was only when I was diagnosed with stage 3 breast cancer in 2015 that the full meaning of this concept became clear to me.

As a consultant breast cancer surgeon, I had extensive knowledge of the disease and how to treat it. However, when I found a lump in my breast at the age of 40, I soon realised how much more I had to learn about living with cancer.
There are so many ways that we as healthcare professionals can help our patients physically, mentally and emotionally through treatment and beyond.

Communication skills

When I worked as a consultant at Ipswich Hospital, I could tell up to five women a day that they had breast cancer.
This had to become a matter of routine in order to help me cope with the emotional toll of constantly breaking bad news.

Liz O'Riordan speaks at the 2019 Macmillan Professionals Conference.

Each consultation was like a ‘box-ticking exercise’. Within the allotted 10-minute slot, I had to tell each person what type of cancer they had, examine them, discuss recommended treatment and book dates for their pre-assessment, surgery and follow-up appointments.

It was not until I was sitting on the other side of the table that I understood what a profound impact a healthcare professional’s words can have. My mind was so busy trying to deal with the news I had cancer that I could hardly take in any more information. All I wanted to do was run out of the clinic room, so that I could shout, swear and scream at the unfairness of my diagnosis. I can still vividly recall every single detail of the consultation.

Good communication skills are crucial to personalising cancer care. It is easy to think of our patients as just another number in a busy clinic, especially with the constraints of treatment targets and mounting pressures on the NHS.
We need to be mindful that our patients will remember what we say and do for the rest of their lives.

Shared decision making
I needed a mastectomy and found it extremely difficult deciding whether to have breast reconstruction. Previously, I would give my patients 100-page booklets full of complex information about the different options and ask them what they wanted to do. However, many women do not think about how their breasts help to define their sexuality or body image and whether they could live without them until they are forced to make that decision. It can be hard to think in a rational way when one or both of your breasts has cancer.

Surgeons may find it difficult to understand why a woman might not want to have a reconstruction or a more complex procedure to recreate a breast. Some people prefer a simple operation so they can recover and return to their routine as quickly as possible.
Others may choose to have a mastectomy instead of a lumpectomy because they want to avoid radiotherapy. Although multidisciplinary teams prescribe the recommended treatment for each cancer being discussed, they do not always consider the wants and needs of the person attached to that cancer.

Treatment targets mean that surgery must be arranged within a month of diagnosis. Against this background, it is challenging to give people the time and information they need to make an informed decision about their treatment. Breast reconstruction is a good example. There are so many different options available, which each depend on an individual’s body shape and health. Giving people too much information can overwhelm them.

Despite the challenges, we need to listen to each person and involve them in a process of supportive discussion.
It is important to explain what alternatives are available and allow time for reflection. Signposting people to charity websites and forums or patient volunteer groups may help them to process the large volume of information. For us as healthcare professionals, it may seem like there is a simple medical decision to be made based on facts. For a person with cancer, a treatment decision could be life changing.

Health and wellbeing information and support

During my chemotherapy, I received many practical tips about managing the gruelling side effects from other people with breast cancer. For example, they recommended a toothpaste for my bleeding, ulcerated gums and suggested what to eat and drink when I lost my sense of taste. As these insights were so valuable, I wrote *The Complete Guide to Breast Cancer* with another doctor who had breast cancer, Trisha Greenhalgh. We wanted to share the tips that we had learned to help us cope with the side effects of treatment.

I would recommend taking the time to ask your patients which websites, forums, books, blogs and apps they have found useful. You can then signpost every newly diagnosed person to accurate, safe and accessible sources of health information.

Quality of life

High-quality, personalised cancer care is not just about low mortality and recurrence rates. There is no point in treating someone with the latest drugs and procedures if their subsequent quality of life is poor.

Among the challenges of survivorship can be coping with chronic pain, fatigue and depression. Some people experience infertility, loss of libido and an altered body image, and many face financial difficulties. There can also be a fear of recurrence on an almost daily basis at the beginning, or a feeling of survivorship guilt if a friend with cancer dies.

I believe that as a medical profession, we must do more to meet the ongoing holistic needs of every person living with cancer. We need to balance the clinical and non-clinical aspects of care and educate multidisciplinary teams about what local support services are available. For example, I did not realise that the hospital where I worked had a sexual counsellor for people with cancer until I returned to give a talk as a patient.

It is important that primary care staff know how to treat the side effects of cancer treatment and recognise ‘red flag’ symptoms of recurrence. We must also ensure that patients are aware of possible symptoms and understand the procedure to see a member of their cancer team again. Rapid re-access to the cancer clinic can help to minimise the mental anguish that people may experience if they have a worrying symptom.

I welcome the commitment in the NHS Long Term plan to ‘introduce an innovative quality of life metric to track and respond to the long-term impact of cancer’. Personalised cancer care means putting an individual’s care and support needs before, during and after treatment at the heart of our work.

You can buy Liz’s book *The Complete Guide to Breast Cancer* (5% of profits go to Macmillan) from any online bookstore. To read her blog, visit **liz.oriordan.co.uk**

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Resources

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