Maximising the Health and Well-being for People following a Cancer Diagnosis across Wessex

Executive Summary

In July 2018 the Wessex Cancer Alliance and Macmillan Cancer Support brought together over 70 health and social care professionals, managers, commissioners and (most importantly) people affected by cancer to identify the services/resources required to enable patients to maximise their health and well-being following a cancer diagnosis.

It was evident that there are many good services/initiatives happening across Wessex but many patients are either unaware of or unable to access them. In some cases, patients are only informed of them at the end of active treatment – and in many, if not all, cases patients wished they had been aware of them from the point of diagnosis.

Patients identified the following key elements they would like knowledge of and be able to access as being:

- Psycho-social support – including spiritual care
- Knowledge of local services - a website which includes this information and more
- Financial and employment advice
- Diet and life-style advice – including physical activity
- Potential side and long term effects of their cancer treatment

A named Clinical Nurse Specialist or Key Worker was seen as vital in terms of patients feeling well supported – we need to be mindful of the 10% of patients who do not have one. It was also evident, that specialist health care professionals cannot provide all the support that patients, family members and carers require throughout their treatment pathway and beyond.

As the majority of people attending were self-selected, we saw under-representation from harder to hear groups. We therefore need to consider how to best engage with these cohorts.

This document will be shared with key stake-holders to agree a consistent and equitable approach to services across Wessex in order to help patients maximise their health and well-being, from the point of diagnosis.

Background

The Wessex Cancer Alliance works with local provider and commissioning organisations to support the implementation and delivery of the NHS England Five Year Forward View and the National Cancer Taskforce Strategy. They both outline a commitment to ensuring that '*every person with cancer has access to the elements of the Recovery Package by 2020*'. The roll out of these interventions will better support and improve the quality of life of people living with and beyond cancer.

The Recovery Package has four main elements:

- Holistic Needs Assessment and Care Planning
- Treatment Summary
- Cancer Care Review
- Health and Wellbeing Events

These form part of an overall support and self-management package for people affected by cancer. This includes support in undertaking physical activity as part of a healthy lifestyle, managing consequences of treatment, information, financial and work support.

Macmillan Cancer Support states that Health and Wellbeing Events are designed to help people affected by cancer and their family and friends get the support they need during and after cancer treatment.

They can provide information and support on:

- Benefits and other financial support
- How to get back to work
- Diet and lifestyle
- Long-term side-effects of treatment
- Specific cancers
- Local services.

Evidence has shown that patients who attended a Health and Wellbeing Event have:

- Better knowledge of the signs and symptoms of cancer recurrence and consequences of treatment.
- More confidence to question or challenge information and make informed decisions about their health.
- More confidence to deal with the physical discomfort and emotional distress associated with cancer and its treatment.
- A strong sense of reassurance - even if the services are not needed at that time, they know what's available and how to access them in the future.

There is some evidence from the evaluation of the Manchester model (Macmillan Cancer Support) to show that Health and Wellbeing Events can help provide better patient outcomes, reduce unplanned admissions to hospital and improve the quality of patient care through:

- Delivering health care messages in an informal and relaxed setting.
- Earlier intervention to address concerns and worries will lead to improved outcomes.
- Giving people direct referrals where necessary, making it easier to access relevant services for the support they need.
- Sharing techniques to help patients self-manage their health and well-being
- Creating the opportunity to meet other people with similar experiences, providing reassurance, reducing anxiety and the sense of isolation, for both people living with a cancer diagnosis, carers and families.

However, across Wessex (Hampshire, the Isle of Wight and Dorset) these events have developed in a very ad hoc way, often focused at the end of active treatment and there is little robust research available that shows that they do indeed significantly improve the health and well-being of people affected by cancer.

The Wessex Cancer Alliance is committed to ensuring that, following a cancer diagnosis, everyone is given the information and support required for them to maximise their health and well-being and that there is an equitable and sustainable provision of care and support across Wessex. To this end, a group of patients, carers, health care professionals, managers and commissioners were brought together to identify what matters most to patients, what works and what can be rolled out and/or replicated. Although diverse in terms of the varying professions etc. attending, it should be acknowledged that it was not so in terms of socio-demographics or ethnicity.

To do this, facilitated conversations were based around the patient pathway. That is:

- At the point of diagnosis
- During treatment
- At the end of active treatment
- And beyond

The Findings

Patients were asked what matters most to them in terms of their health and well-being:

At all points of the pathway:

- Someone to talk to – this could be family member, a peer (Support Group member), volunteer at an Information and Support Centre, member of the multi-disciplinary team and/or someone in Primary care

- Continuity of care – dependent on good communication between Health Care Professionals, Primary and Secondary Care, specialist departments within hospitals plus Secondary and Tertiary Care

- Good information and sign-posting to services available in the community – this is needed at the point of diagnosis not just at the end of treatment
- Holistic support – clinicians seeing the person not just the diagnosis
- Someone to encourage and support you and to sort matters when feeling over-whelmed; regular review of progress with a 'support worker'
- A 'one stop shop' to go for information, for example:
    - A Wessex specific website
    - A centralised, accessible, user friendly support center
- Privacy and appropriate places for conversations with professionals
- Information for schools

At the Point of Diagnosis

- A telephone contact number pre-treatment and a follow up call afterwards with awareness that no advice is too basic to give
- A fast follow-up by Support Worker following a GP referral. This should include an assessment with personalised support on staying healthy, not just a 'tick box' exercise
- 10% of patients do not have a Cancer Nurse Specialist (CNS) – they need information and support
- An accurate understanding of what the cancer diagnosis means from the outset – with a clear treatment plan written in 'lay-man's' terms for the patient and their GP. Health professional to write to patient after an appointment, summarising what was discussed and avoiding jargon
- A 'satnav' or map to help to navigate through all the processes during diagnosis and treatment, understanding what the different disciplines do and who to speak to about what - to have easy access to relevant, accurate and helpful information
- Information regarding legal, financial, health and well-being (including exercise and diet) issues
- Reminder to give family/next of kin your accounts and passwords if they need to take over

During Treatment

- Improve speed of communication between primary and secondary care regarding surgery, treatment and follow-up

- Improved communication between different specialist departments when patients are treated by different teams and/or hospitals

- Specialist dietary advice tailored to particular cancers and treatments

- Improved information on the effects of chemotherapy and steroids e.g. on appetite, energy and sleep

- Home visits from community cancer support worker to assess practical help and specific services needed e.g. play therapists for children

At the end of active treatment

- Difficulty in defining when this is – it will be different for different tumour sites

- Help with adjusting to the 'new normal' – the vulnerability you feel at the end of treatment. Feelings of low worth and self-esteem.

- Honesty about the support you can expect from GP and what is available. Value of support from GP surgery. Who can you phone if feeling really sad/lonely/vulnerable – or just having a bad day.

- Importance of CNS - concerns re patients who don't have one – but can be perceived as too busy to call. Treating the cause of the problem - not just the side effect.

- Difficulty in navigating the system. Gaps and lack of communication when under care of several hospitals. Out of county referrals make support at home very difficult - e.g. treated at RMH but live in Wessex.

- Services working together - a Directory of Local Services. Charities collaborating to clarify who provides what and utilising resources to their best.

- Importance of peer support and peers understanding re feelings/emotions/experiences - shared experiences. Knowledge of Support Groups Befriending schemes - GP surgery befrienders

- Tailored expert patient programmes. H + W events - needed earlier in the pathway e.g. half way through treatment. Information re healthy eating and alternative therapies e.g. mindfulness.

- Timing of reconstruction surgery - if limited within 2 years - e.g. breast reconstruction - may not be ready to have that surgery but potentially could be 5 years later.

- Individuals navigating support and knowing where to go. Given choice/options where/what support available. Loops in the chain often missing

- Advice on exercise - on what you should and shouldn't do. Too shy to speak up in a generic class. Option for activity based support. Support and management with side effects - e.g. lymphoedema, tamoxifen and someone professional who will listen and support management.

- Support for family members - support group for peers and family, being mindful of patient privacy and confidentiality issues.

- Acknowledged that a percentage of people will not want anything else past treatment.

And beyond

There is a reasonable amount of literature on the heightened psychosocial needs of people once they're discharged. We know that this can often be a time when people struggle to cope with the consequences of their treatment – particularly if these are predominantly psychological and family/friends assume patients will be 'back to normal'.

There is also evidence that those patients with higher levels of depression and lower self-efficacy (confidence) to manage illness related problems around the time of diagnosis predicts poorer health related quality of life 2 years later. This supports the notion of providing holistic support to patients early in the treatment pathway. (CREW [1])

Wider conversations are needed:

- To increase awareness of people about living beyond cancer and better outcomes for people now – more positive language like living with and not fighting cancer is important. Need to encourage people to see how they can get their mind, body and spirits around a future with cancer. Not in the public consciousness yet.

- To clarify the role of the healthcare professional at this point. If people are offered choices and don't follow the advice at the end of treatment when does the health system say it is over to the individual. Or do they have a continuing role to educate so as not to incur relapses etc. Low resilience - how to assess and empower patients

- To have a co-productive discussion about the expectations of where the support will come from. If there is not the capacity in primary care to offer support for those living with cancer and the community and voluntary sector is being expected to pick this up, then there needs to be a co-productive dialogue about how they can happen (including with local authorities who are often commissioning voluntary sector social and community support).

- To enable people to build exercise into their lives – need support from employers, local authorities etc. Male specific activities such as Men's Yoga.

- To increase awareness of disability rights with employers. Employers often don't understand cancer in relation to the Equality Act – and that protection is from the point of diagnosis and for the rest of a person's life.

Discussion

Let's not lose what works:

- At discharge a conversation and signposting about the things that are most important to the patient
- Return to work courses – e.g. Victoria's promise
- Self-management courses
- Exercise programmes
- Cancer Support Centres

What's still needed?

- Unlimited counselling – 6 months / 6 years after discharge
- Support with side effects – knowing where to go / who to ask long after discharge

What do we need to think about for Wessex?

- To ensure there is consistency/quality of service across the pathway

- Make links to those providing support to other long-term conditions (need to overcome silo working in conditions but also across different commissioners)

- How to engage those who are seldom heard – and linked to this how can people / communities be enabled to create their own responses to meet their needs

- Ensuring there are different ways for people to access information and support about what people can do for themselves

- Having a 'suggest a resource' function on the new Wessex website

- Attitudes of some consultants e.g. to patients with MH issues as a result of treatment and ongoing recognition that this will be the first time the person has been this process (rather than having the experience/ knowledge and power that the consultant will have)

Next Steps

- Share the report with the delegates and more widely with key stakeholders across Wessex
- Identify gaps in provision across Wessex
- Discuss with key stakeholders at local level: Dorset, Southampton, Portsmouth, Hampshire and the Isle of Wight – identify appropriate Steering Groups, meetings to attend
- Consider how best to address the needs of a more diverse community
- Define the key elements of support and information of information required by patients and all stages of the pathway in order to maximise health and well-being

Appendix – Mapping Exercise – Services Identified.

1. Dorset Advocacy
2. Exercise that is suitable/relevant for tumour type - e.g. Pink Pilates
3. Tailored expert patient programmes HOPE courses.
4. Macmillan Information and Support Centres
5. Wessex Cancer Trust
6. The Living Tree
7. Living Your Life After Cancer
8. The Romsey Support Centre

References:

Foster et al CREW trajectories published