

MACMILLAN INFORMATION SERVICE UPDATE & LWBC/PERSONALISATION DEVELOPMENT PLANS

This document highlights key points from the Macmillan Information Service Annual Report 2018 and a presentation to the Trust Cancer Board on 17.4.19.

The NHS Long Term Plan 2019 states ‘By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support (Section 3.64)’. The Macmillan Information Service aims to deliver this personalisation agenda by:

- Providing high quality, personalised information and support for anyone affected by cancer, as well as carers and family members, at each stage of the patient’s pathway. Tailored support includes providing practical, emotional and financial support, as well as signposting and onward referrals, within a non-clinical, calm and relaxed environment.
- Complementing the clinical support offered by the trust, to ensure holistic support and the best possible patient experience.
- Being a resource and support for Health and Social Care Professionals within both the trust and in the community, to support the delivery of Care Plans following Holistic Needs Assessments by CNS teams.
- Leading and co-ordinating the delivery of generic Health and Wellbeing Events (HWBE) for patients who have finished treatment, facilitating a smooth transition to community services and supported self-management.

Our team consists of two full time staff (one permanent and one temporary position) and five active volunteers. We run our service from the Jayne Garforth Macmillan Unit at CRH and the Greenlea Oncology Unit at HRI. Our key statistics from the 2018 Annual Report include:



The Macmillan Information manager, Helen Jones, also has a Project Management role, supporting the trust’s delivery of the Recovery Package for cancer patients, working closely with Christopher Button, Lead Cancer Nurse, and the CNS teams to implement Holistic Needs Assessments, Care Plans, Treatment Summaries and Health and Wellbeing Events/support. Currently in the trust most teams are offering some kind of HNA on diagnosis and resulting Care Plans are just being shared with GPs and the patient. National guidelines state that HNAs and Care Plans should also be offered at the end of treatment and if the patient has a recurrence or becomes palliative, which is less consistent in the trust. The use of Treatment Summaries is at an early stage as is the case regionally and nationally. Some teams are consistently referring patients to the generic HWBEs, some are less consistent. Several teams are delivering site specific HWBEs, and more in depth health and

wellbeing programmes, as well as running support groups; others are not. As a trust we are working closely with the West Yorkshire and Harrogate Cancer Alliance to deliver the national strategy and standards. The alliance has also identified regionally a lack of support for patients living with a palliative cancer diagnosis but not yet needing specialist palliative care, which we also plan to address.

2019 Personalisation Development Plans for

a) Macmillan Information Service:

- Secure Staff Posts –Assistant Manager, Mandy Davies funded only until September 2020. Potential to expand the staff team to include support workers?
- Personalising Support for Cancer Patients – role as a cancer hub - supporting the delivery of Care Plans but potentially looking to offer HNAs/Care Plans from the information centre, particularly at the end of treatment.
- Wider Promotion of the Service – especially at HRI. Signs; Information Pod in the main entrance; patient newsletter; webpage/Facebook/twitter – aim to support more than 32% of newly diagnosed patients in CHFT.
- Expand the Volunteer Team – only 5 volunteers currently; new patient befriending role currently being established.
- Develop and co-ordinate a new Health & Wellbeing Programme across the trust – establish an equitable offer of HWB support across tumour sites.
- More Patient Engagement & Co-design – identifying support gaps and new support groups/courses/ events e.g. with patients facilitating on the HOPE Course. Patient Focus Group for personalisation/ service development – planned for June 2019 – inviting patients to co-design this new HWB programme.
- Closer working with GPs across Calderdale and Huddersfield - raise the profile of the service to GPs in order for them to refer/signpost to us following their Cancer Care Reviews (service is not only for people under active treatment).
- Improved Community Links for Patients – closer links with social prescribing teams – option to potentially become a personalisation test site for NHSE working with the Cancer Alliance.
- Closer engagement with BAME and hard to reach communities.
- Maintain and develop the high quality service provided by the Macmillan Information Centre team.

b) CHFT:

- Support the cancer teams in their delivery of the Recovery Package -to consistently offer HNAs on diagnosis and to introduce HNAs at the end of treatment/on palliation; introduction of eHNA (electronic); more consistent sharing of Care Plans with GPs; progress Treatment Summaries in partnership with the Cancer Alliance.
- Working with clinical teams to deliver the new HWB programme across the trust.
- Introduction of a consistent Patient Education Programme (similar to current HWBEs) after treatment has finished – to allow safe follow up for Risk Stratification.
- Ideal to offer PEPs/HWBEs at the end of treatment to all patients regardless of high/mid/low risk – to include – lifestyle advice/physical activity/managing the emotional aspects of cancer/signs of recurrence/symptom management.
- Working with the new Macmillan Prehabilitation Post Holder to look at PEPs/HWBEs between diagnosis and the start of treatment – evidence from current HWBEs is that people want information earlier.
- Introduction of the ‘Thinking Ahead’ programme for palliative cancer patients who do not yet need specialist palliative care (may or may not be receiving treatment)– includes early end of life conversations and care planning/benefits and financial advice/living with uncertainty/ links to support services such as hospices and chaplaincy.
- More active signposting to physical activity programmes as a way to manage side effects of treatment and significantly reduce the risk of cancer recurrence for some tumour groups e.g. (40-50% reduced risk in colorectal and breast cancers).