

Freedom of Information Request

Ref: 21-054

3 February 2021

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

1) What support do you offer for the family members of patients being treated for cancer within your NHS Trust? (Support can include anything that would contribute to the emotional well-being of an individual, such as support groups, counselling or advice).

Macmillan Cancer Support Workers:

Macmillan Cancer Support Workers (CSW) work alongside clinical teams across all cancer specialties such as Urology; Breast; Colorectal; Acute Oncology; Gynae; Haematology, CUP; Lung; Upper GI; Skin. The role of the CSW is:

General information and support

To provide general information and support to patients and their carers about cancer and cancer services, to enable people to navigate the health and social care system and make informed choices about their cancer and their life. A key aspect of the role involves daily and direct (e.g. face to face and telephone) communication with patients, relatives, carers and other health and social care professionals. Since the pandemic all support is provided via the telephone or video calls.

Co-ordinate support for people with non-complex needs

To proactively identify the needs of people with cancer and carers, using knowledge, approved tools, and procedures to support people to access the right help to meet their needs. They provide appropriate advice, and escalate to the registered practitioner where appropriate.

Co-ordinate education and support for people with non-complex needs

To coordinate access to the right information and education resources at the right time to support people in making informed decisions about aspects of their own care and lifestyle, in order to enable independence and support self-management as appropriate.

All CSWs are Psychological skills level 2 trained so provided emotional support to patients when needed.

Pre pandemic support was face to face or telephone and primarily using the Macmillan Recovery Package Holistic Needs Assessment: The CSW can provide information and support on the following

- Practical issues e.g. money, work or household tasks
- Family/Relationship e.g. changes in your relationships
- Emotional concerns e.g. depression, fears, worry, anger or anxiety
- Spiritual/Religious e.g. loss of faith, loss of meaning or purpose
- Physical e.g. appearance, eating, fatigue
- Other concerns e.g. advice on healthy lifestyle changes, such as stopping smoking, diet and cutting down on alcohol

At present support is generally provided over the telephone or via video calls.

Patients can be referred to the CSW team by their clinical team or can self-refer.

Information Centres:

Weston Macmillan Support Centre

The centre is open Mon – Fri 8am – 5pm. The centre is available to anyone that is affected by cancer, patients, families, carers, friends and professionals. The Centre provides information in the form of literature e.g. booklets, information sheets, leaflets etc. (not all Macmillan based, literature is also available for children), support through listening ear service by Macmillan Centre Manager and Macmillan Cancer Support Workers – all trained in Level 2 Psychology Skills. The centre also signposts to local support groups, services, counselling, citizen advice bureau (CAB – whom is also on site x2 a week outside of pandemic). The Centre also runs (outside of pandemic) Look Good Feel Better sessions at present for just female patients going through cancer treatment.

Bristol Cancer Information and Support Centre (CISC)

The CISC is currently closed due to the pandemic. All patient/carer/staff queries are directed to the Bristol CSW team.

When open the CISC operates Monday to Friday 9-5pm. The centre has a vast selection of information leaflets available to anyone visiting the hospital, patient/carers/supporters/staff. Staff and volunteers in the centre offer a listening ear service for people who need a quiet

space to talk. Support is provided by the team for financial enquiries, wig referrals, signposting to support groups and services, local counselling services, Look Good feel Better sessions.

Health and Wellbeing Events:

Pre pandemic the Trust ran three health and wellbeing events for patients and their carers/supporters/family members

First Steps – for those patients with a new cancer diagnosis

Next Steps – for curative patients who have completed treatment

Living Well with Advanced Cancer – for those patients with a prognosis of 6-36 months

These events cover the following topics:

- help and support available
- diet and nutrition
- managing fatigue
- exercise
- emotional wellbeing.

At present face to face events are on hold. These sessions are available on the Trust website as a series of short films. Patients are referred by the clinical team/CSWs to these sessions or a patient can self-refer. All referrals/invitations are managed by the CSW teams. Event posters are displayed around the Trust and information flyers are with all CNS teams to share with patients.

2) Does your NHS Trust provide any tailored support specifically for young people (under 25s) who have family members being treated for cancer?

No

3) If so, please could you provide details.

Not applicable

4) Are services actively offered to patients' family members, or do they have to approach the Trust themselves to request support?

Yes all services provided by the Personalised Care and Support Team are offered where appropriate to family members.

Macmillan Centre

All services are offered internally and externally:

- Leaflets in letters and packs to patients

- Physical presence in the hospital on a main corridor
- Word of mouth: Consultant Teams; CNSs; CSW; Outpatients; Health & Wellbeing events; previous users of the Centre
- Health and Wellbeing Events
- Social Media, local media
- Macmillan Centre Newsletter (introduced in 2020)
- Internal communications - raising awareness for staff outside of cancer services
- Pop up Stall at local Health Centre (currently on hold due to pandemic)
- Established Links with local support groups

Bristol Cancer Information and Support Centre

The centre is open to all visitors to the Trust. There are information hubs around the Trust with a variety of information and support literature available to take away.

Macmillan Cancer Support Workers

The Macmillan Support Workers liaise directly with patients at diagnosis, during treatment and on the completion of treatment. During Holistic Needs assessments/conversations patients would be made aware of support that is available for them and their supporters. CWSs as part of support to patients also when appropriate support family members, however it is to be recognised that the patient is the primary.

In Bristol referral to the CSW team is generally made by a member of the clinical team however a patient can self-refer to the team.

Promotion of the Health and wellbeing events has been via the Trust facebook page and twitter accounts. The CSW team made a short video at the start of the pandemic which was shared on social media to assure patients that the team was still here to support them.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Director of Corporate Governance
 University Hospitals Bristol and Weston NHS Foundation Trust
 Trust Headquarters
 Marlborough Street
 Bristol

BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust