Macmillan Support and Information Service

Our first two years

September 2014
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Foreword
It gives us great pleasure to share with you this report of our first two years. Its purpose is to provide insight into what our services are, what they do, how they have developed and what we plan to do over the next three years.

There have been a number of significant developments during our first two years - all of them in response to the supportive care needs of patients and families. For this we thank our team, University College London Hospitals NHS Foundation Trust (UCLH) and Macmillan Cancer Support for supporting our work and vision.

We hope you enjoy reading about our developments and plans for the future.

Ms. Lallita Carballo and Dr. Hilary Plant
Clinical Leads for Supportive Cancer Care and joint Heads of the Macmillan Support and Information Service
1. Introduction

Who are we?

The Macmillan Support and Information Service is made up of a team of experienced, creative and dedicated health professionals, assisted by volunteers, who are brought together by a passion to support people through their experience of cancer and red cell disease. The support we provide is for all; patient, family and friends at every stage of their experience - from suspected diagnosis through to life during and after treatment.

As a team we are drawn from many different disciplines; Nurses, Physiotherapist, Radiographer, Complementary Therapists, Counsellors, Psychologists, Welfare Rights Advisers, Hairdresser, Editor and Manager. The volunteers we work with contribute further experience, knowledge and skills.

Together we provide a service that aims to respond to each individual’s needs. We strive to reach all people with cancer and red cell conditions and those close to them and work collaboratively with our colleagues in the multi-disciplinary teams at UCLH and across London Cancer.

1.1 Why are we here?

As health professionals, we know from experience that a diagnosis of cancer can be challenging to patients and their families in a variety of anticipated and unexpected ways.

Living with a red cell condition also entails complex and ongoing challenges that require flexible support in a variety of guises. The Macmillan Support and Information Service offers a wide range of easily accessible, innovative support and information which enables patients and their loved ones to live with and manage treatment and life afterwards as well as possible.

1.2 Our vision

Our vision for the Macmillan Support and Information Service is to meet the needs of patients and their families and friends by providing access to individualised, supportive cancer care which is integrated with the experience of treatment and follow-up. We aspire to lead in the development of innovative interventions that support and improve the experiences of people with cancer and their families.
We will evaluate, collaborate and share our knowledge with others to ensure that patients get the very best support, and our clinical colleagues see the service (and supportive cancer care) as an intrinsic part of every patient’s journey.

We believe that, with the right support and information, most people can better cope with a cancer diagnosis and better manage their day-to-day lives. Through our trained staff and volunteers, programme of support activities and workshops, and services such as welfare rights and benefits advice, counselling and complementary therapies, our goal is to ensure that everyone who accesses us:

- Feels cared for, listened to and understood by people who have the knowledge and experience to help
- Receives the information they need and the time to digest, understand and work through it
- Receives the practical support they need.

1.3 Our philosophy

The philosophy underpinning the Macmillan Support and Information Service is one that promotes recovery through personal empowerment and self-management. Patients will be enabled to recognise their own strengths, coping mechanisms and resilience so they can make choices about their care and support needs.

This approach will facilitate patients to self-manage their care and recognise the need to take personal responsibility. Assisted by our programme of support, we aim to rebuild confidence and a sense of wellbeing through structured workshops and courses and innovative support models.

We will, at all times, work with our clinical teams to respond to the needs of the patients and the families they care for and so maximise opportunities for all cancer patients to receive the support and information they require.

1.4 Our strategic objectives

Objective one

To support patients and families to develop the personal resources to manage their diagnosis of cancer, its treatment and the consequences of treatment.

Objective two

To work with and support all clinical teams to integrate supportive cancer care as a part of routine clinical practice.

Objective three

To be leaders in supportive cancer care by innovating, developing and evaluating new models of care.
2. Our services
The Macmillan Support and Information Service is made up of seven separate but closely interlinked services providing support for people with cancer and red cell conditions and their families. Many of these services pre-date the opening of the University College Hospital Macmillan Cancer Centre in April 2012. The pump prime funding from Macmillan Cancer Support (£650,000) has allowed us to expand our workforce. The opening of the new Macmillan Support and Information Centre provided the environment to draw these services together in a more strategic and integrated way, and enable better resource use and more equitable access for all.

Our services comprise:

- Drop-in support and information in the Living Room
- A programme of sessions to support and facilitate self-management when living with cancer and red cell disease
- Information Specialists
- Welfare and benefits advice
- Psychology and counselling services
- Complementary therapy sessions
- Wig fitting

Twenty-five per cent of patients who attend the Cancer Centre use the services of the Macmillan Support and Information Service. We undertake a survey of our visitor’s ethnic background twice a year and this reveals that we have a diverse group of users, reflecting the diversity of total visitors to the Cancer Centre.

2.1 The Living Room
The experienced team of health professionals and support staff in the Living Room offers a welcoming and informal space for those affected by cancer and red cell conditions. The Living Room is a non-clinical, peaceful environment that facilitates processing of various issues, either as a family or with the support of a healthcare professional.
The work of the Support and Information Specialists in the Living Room requires a skilful blend of responsiveness, boundaries, practical knowledge and psychosocial education. It entails gathering information, making an assessment and planning an intervention.

Taking time to gently probe beyond a request for a leaflet often reveals a whole raft of concerns about living with and beyond cancer. Thus, interventions in the Living Room may include identifying an information booklet, advice on returning to work or, most often, an opportunity to be listened to and emotionally held whilst trying to make sense of the existential challenges faced when diagnosed with cancer.

The non-referral, drop-in approach of the Living Room allows people to seek help and support when they want to and to set their own agenda. The Living Room is valued by visitors as a place to think and reflect on what they may have been told at any point during their treatment pathway.

Subject of enquiry in the Living Room

Ten most common cancers recorded for visitors to the Living Room from April 2013 to March 2014
Since the Cancer Centre opened, there have been approximately 550 visitors to the Living Room every month. Our data shows that we see more women than men with the majority aged between 40 and 70 years. Every day more than half of our attendees are people who are making a return visit to meet a Support and Information Specialist, attend a group, use the space to quietly reflect or, increasingly, to meet other patients.

Interactions with visitors in the Living Room most commonly focus on; talking about cancer, anxiety and fear of death, loneliness and isolation, loss of confidence, impact on lifestyle and identity, financial and employment concerns and impact on relationships. The pictorial diagram below shows how we have developed the service to place the person at the centre of what we do.

Model of care in the Living Room

2.2 Programme of sessions to support and facilitate self-management

Diagnosis, treatment and subsequent transition into survivorship presents well-described and significant physical, emotional and social challenges for many patients with cancer (National Cancer Survivorship Initiative, 2013). Evidence emerging from research also shows that many cancer survivors have significant unmet needs (Armes et al, 2009).

In our first two years we have, in conjunction with the clinical teams at UCLH, designed and delivered an innovative programme of support responsive to expressed patient and family need.

This programme has been developed in line with national strategic objectives and to support UCLH in improving patient experience in response to the annual National Cancer Patient Experience Survey.

Recognising the importance of self-management in promoting personal responsibility is fundamental to the development of our programme. Our aim is that the programme will enable people to recognise and build upon their personal resilience and coping mechanisms so they feel confident to make well-informed choices about their survivorship needs. Attention is given to the multi-faceted effects of cancer and treatment on physical, emotional and interpersonal functioning, and the natural interaction of all these factors.

The evolving programme includes group workshops on support and information (fatigue, sleep, exercise diet, getting started and what next) and recovery days, as well as creative word, art and yoga. We host popular sessions such as Look Good Feel Better and regularly run the H.O.P.E course (Helping Overcome Problems Effectively) for patients and carers.
We work with Breast Cancer Care to facilitate the Moving Forward course for women with breast cancer and host and support the Laryngectomy Group and a cervical cancer support group with Jo’s Trust.

We set up and establish support groups based on expressed patient need, our most recent being a group for men with penile and urethral cancer (the first of its kind in the UK).

We are open to discussing new opportunities and supporting ideas and suggestions from patients, their families, staff and interested charities.

2.3 Evaluating the Living Room and programme of self-management and support

We evaluate everything we do within the Macmillan Support and Information Service for a number of reasons; primarily so that we know we are providing the level of supportive care that patients and their families want and feel satisfied with, and to facilitate us to respond to any changes needed. We also require feedback to ensure our services are of the highest quality, to enable us to promote them throughout UCLH and beyond. Furthermore, we want to champion the work we do nationally to influence improved experience for patients and advocate the most successful elements of self-management.

All of the services we provide ask for feedback. For example, in May 2014, we asked just over 100 consecutive visitors to complete a survey of their experiences in the Living Room:

• 71 per cent of 104 visitors who completed the survey said that they came into the centre to talk to someone or because they knew someone would be available to support them
• 94 respondents said that they would make a return visit.

“The centre, its atmosphere and especially its staff provide such tremendous support for patients. It has helped to make the unbearable more bearable for me and, I am sure, for many more.”
I felt able to explore issues I had not been able to discuss elsewhere

The person I saw was clear and easy to understand
2.4 Information Service

Information - both written and verbal - as well as the assessment of an individual’s information needs is a fundamental element of the Macmillan Support and Information Service. We provide a very well-stocked library of booklets and leaflets and further information is readily available online. Visitors to the centre are welcome to browse resources on their own or be supported through conversation with one of the Specialists.

In addition to this, the Macmillan Cancer Information and Support Specialist is responsible for delivering a patient information strategy across Cancer Services, ensuring that the process of producing written information runs as smoothly as possible, and that the multi-disciplinary teams feel supported in delivering high quality resources to patients.

In 2013 a new role of Patient Information Officer was created to support the clinical teams in the development of their information. This editing role ensures that leaflets are more consistent and produced in a more efficient manner. This post also co-ordinates patient review, ensuring that the language used in each leaflet is appropriate and comprehensive.

Since developing a flowchart to guide clinicians through the process of developing patient information and show how the information team can support them, there have been 23 leaflets sent to the team for their input.

A series of projects to promote the Macmillan Support and Information Service is also underway, including open mornings for patients and staff, promotional posters, pull-down banners in the Tower (atrium of the main hospital building), a Twitter account, updated web and intranet pages and outreaching to other sites.

Follow us on Twitter: MSIS at UCLH
@SupportandInfo
2.5 Psychology and Counselling Services for people affected by cancer at UCLH

The impact of a diagnosis of cancer may be felt in a variety of ways – both by the individual and also by their family and friends. Psychological and emotional care has been shown to be important in helping patients to manage their illness and its treatment, and in supporting people to recover well in the longer term.

The Psychological and Emotional Care Team works within the Macmillan Support and Information Service and is made up of three Psychologists and three Counsellors, each with individual areas of expertise. Our Psychologists and Counsellors offer individuals who feel that they are temporarily not coping or are overwhelmed by their diagnosis the opportunity to talk through how they are feeling in a safe and supported environment.

The team utilises a range of evidence-based interventions such as cognitive behavioural therapy, mindfulness-based interventions, narrative therapy, existential therapy, systemic therapy, specialised cancer-related interventions and a range of counselling approaches. They are also able to provide proven self-help techniques to minimise treatment side effects and enhance quality of life both during and after treatment.

A series of sessions may be offered on an individual, couple or group therapy basis. The service is free and available to UCLH patients and their families on referral from either the clinical team or specialist staff within the Macmillan Support and Information Service. Patients are most commonly seen as an outpatient but may also be visited on the inpatient wards.

All Psychologists and Counsellors are accredited and work within their professional code of practice. Experienced trainees may also join the team at times, and may be supervised to see clients.

Clinical referrals continue to rise and from April 2013 to March 2014, a total of 2,323 appointments were made.

The Counsellors and Psychologists are also involved with advising the clinical teams and training, educating, supporting and supervising colleagues working with cancer patients and their families. It is anticipated that within the next year, the outcomes of a series of sessions with the Psychological and Emotional Care Team will be evaluated utilising an outcome measure agreed by London Cancer.

2.6 The Red Cell Haematology Psychology Service

The Red Cell Haematology Psychology Service is available to all people using the Adult Red Cell Haematology Service at UCLH. The service operates on Mondays, Tuesdays and Wednesdays and is embedded within the multi-disciplinary team. It provides inpatient, outpatient and day patient one-to-one and couple/family input.

The Psychology Service is actively engaged in building links with other relevant services both within UCLH and with other Trusts. The service is well used and is increasingly considered an integral part of care by patients attending the Red Cell Haematology Service.

In 2013 a Red Cell Haematology Volunteer Service was established in which five specifically recruited and supervised volunteers provide informal support, help with access to services and share service-related information to red cell haematology patients. Plans are now in place to provide workshops for patients to help manage the emotional challenges of their conditions. There will also be a series of focus groups to gather feedback about psychosocial care needs and to guide future service developments. Additionally, there are also plans to improve liaison and links with other external services providing care to red cell haematology patients.
2.7 Welfare and benefits advice

For many people, money worries and unexpected costs can be almost as stressful as cancer itself, impacting on their ability to cope or focus on their own wellbeing. Research by Macmillan Cancer Support shows that 83 per cent of people with cancer incur additional costs of around £570 per month (Cancer’s hidden price tag, April 2013). Indeed, our own survey showed that 19.6 per cent of people who attend the Living Room include welfare and benefits issues within their enquiry.

In the Macmillan Support and Information Service our Welfare Rights Advisers, supported by volunteers, see approximately 88 patients per month both on the wards and in the Cancer Centre. The team provides information and advice to cancer and haematology patients and their relatives and carers, helping them to access the financial support they are entitled to. Volunteers focus on a more basic level of support such as helping patients to complete forms in applying for grants, and collecting the right supporting information. This enables staff to deal with more complex, difficult cases.

Being part of the wider Support and Information Service which caters to patient’s holistic needs means that the Advisers are able to refer people on for other types of help too. This ranges from reliable cancer information explained in a way they can understand, to counselling, dietary advice or group activities.

“The lady who helped me was very confident and knowledgeable. I can away feeling that all areas had been covered and I was receiving what I was due.”
2.8 Complementary Therapy

The Complementary Therapy Service is available to patients receiving treatment for cancer or haematological conditions at UCLH.

The Complementary Therapy Team is based within the Macmillan Support and Information Service. Outpatient appointments take place across the Cancer Centre and visits to inpatients on the wards can also be arranged. The team comprises paid members of staff who work alongside and supervise a number of volunteers.

The team has continued to provide a consistent number of individual therapy sessions this year - 3,504 - to both inpatients and outpatients.

Therapies currently available are aromatherapy, massage, reflexology, reiki and a relaxation group session. A typical therapy session will last up to 30 minutes, including a brief consultation at the beginning.

All new patients are currently being asked to take part in a study to evaluate the effectiveness of complementary therapies against the individual’s concerns.

Although the team is employed by the NHS, much of its funding is through charitable donation. They are particularly grateful for the support of the following charities; Cancer Care (part of the UCLH charity), The Leukaemia and Lymphoma Fund (LALU) and the UCH Cancer Fund.

“Thank you to the whole team for all the support you have provided to me and my family. Being able to access this support and benefit from the complementary therapies has been invaluable.”
2.9 Wig fitting and scarf tying

The wig fitting and scarf tying service is available to all UCLH cancer patients who have experienced hair loss as a result of their condition or treatment.

A trained member of our team provides wig and head wear advice, either within the Macmillan Support and Information Centre or on the inpatient wards. Patients are able to select up to three wigs to order and try on at a fitting session. Our wig fitter is also able to advise on scarf tying. In 2013 we fitted 701 wigs.

“I’ve had the most rewarding wig session. I have found her work helpful and supportive.”

3. Volunteers

Launched when the Cancer Centre opened in April 2012, our volunteer service now has around 70 members who each provide cancer and red cell haematology patients with relevant support, information and activities.

Volunteers have been invaluable to the Macmillan Support and Information Service. We have a team of experienced volunteer complementary therapists, welfare rights volunteers supporting our Advisers and enabling them to reach more people, and a group of volunteers who support the day-to-day running of the Living Room.

Our Look Good Feel Better and H.O.P.E workshops are run with volunteer support and volunteers lead on our art and creative writing workshops, which have had a profound impact on the patients involved. Looking ahead, we aim to recruit more volunteers to help with support and information integration and with fundraising for our service.

Every volunteer role is designed to have an impact on patients and their families and friends and we work hard to ensure that they are also rewarding for the volunteers themselves. Not only do volunteers enjoy what they do because they make a difference, they also gain new skills and experience, make new friends and meet inspiring people.
As one of our Macmillan Support and Information Service volunteers said:

“It’s a truly rewarding experience and an inspiring place to volunteer. Being at the Cancer Centre puts my own problems into perspective and I gain so much from it. The team I support are fantastic and I really feel that I contribute and help support people who need it.”

To find out more about volunteering go to www.uclh.nhs.uk/ccvols

4. Integrating Supportive Cancer Care

Our vision is that access to the services provided by the Macmillan Support and Information Service should be part of routine care and available to patients and families as an integrated part of their experience at UCLH.

To achieve this we have worked closely with the clinical multi-disciplinary teams to understand the needs of the patients they care for and to determine how best our service can respond to such needs. Below are a few examples of the collaborations that have developed as a result of this approach.

Collaboration with site-specific teams: Each multi-disciplinary team has a staff member from the Macmillan Support and Information Service allocated to work with them on relevant projects. For example;

• Lung Holistic Needs Assessment (HNA) pilot as part of a wider project to embed appropriate support and information in response to identified HNA concerns

• Head and Neck workshop following a focus group of patients with a Head and Neck sarcoma and a support and information pilot in May 2013

• Support intervention using web-based and group work to support patients with prostate cancer who are on active surveillance

• Penile support and education group

• Post-Bone Marrow Transplant workshop

• Bladder cancer support group

• Red cell focus group to assess the support and information needs of people living with red cell conditions

• Sarcoma H.O.P.E (Helping Overcome Problems Effectively) course to establish the needs of sarcoma patients at the end of treatment

• Breast ‘Moving Forward’ programme for women with primary breast cancer

• Adult survivors of childhood cancers support and education review

• Working with Clinical Nurse Specialist (CNS) information leads to develop written information

• Closer collaboration with all ward areas to ensure awareness of the service to include attendance by the Specialists at key nursing meetings such as ward handovers and ward-based education programmes

• Pilot proposal for a support and information pod in the atrium of University College Hospital in partnership with the Support and Information Specialists and volunteers

• Plan from September 2014 to include time in the Macmillan Support and Information Centre for all medical students during their cancer module.
5. Developing the skills of professional staff
As a service we have an important role in not only supporting patients and families but also the staff who are often dealing with very complex and highly emotional situations. In the last twenty-four months we have focussed on four keys areas of development to help support and build the skills of staff. These have included:

- Developing and embedding the communications skills training course Sage and Thyme for all appropriate staff
- Developing an infrastructure and working group to implement the London Cancer HNA for particular groups of patients and successfully bidding to be a pilot site to test an electronic version of an Holistic Assessment Tool
- Developing a monthly programme of seminars for clinical professionals in the Cancer Centre around important clinical themes
- Working with the King’s Fund Point of Care Foundation and Macmillan Cancer Support to be part of the Schwartz Round’s pilot programme which started in April 2014.

The Schwartz Round Pilot Team (left to right: Charlie Butler, Michelle Hope, Lallita Carballo, Lisa Anderton, Jonathan Fielden, Sue Gessler, Hilary Plant).
6. Innovation, evaluation and research

Cancer Follow-Up Redesign Project
The UCLH Cancer Follow-Up Redesign Project (funded by Macmillan Cancer Support) aims to address the needs of an increasing number of people living with and beyond cancer. There is national ambition that this growing population of cancer survivors can live healthy and fulfilling lives. However, current service provision does not always facilitate this. Cancer specialist clinics at UCLH are overwhelmed with an increasing number of people attending for long-term follow-up, and are not always structured in a way that meets the needs of those who have finished treatment and are living with the long-term effects of their diagnosis.

The overall aim of this project is to improve the health and wellbeing of people who have finished treatment through a more personalised approach to follow-up. The key aims of the redesign service are:

- To allow those who are suitable and willing to undertake self-management to do so in a safe and supported manner
- To implement elements of the National Cancer Sponsorship Initiative (NCSI), Recovery Package (Holistic Needs Assessment, Treatment Summary, Care Plan, attendance at a Health and Wellbeing event) as endorsed by Macmillan Cancer Support and Cancer Commissioning Groups
- To increase the number of patients who are educated and knowledgeable enough to undertake supported self-management by making information and support easily attainable
- To improve patient experience by eliminating anxiety and waiting for unnecessary appointments, and by adopting a more holistic, individualised approach to care. To develop a system for rapid re-entry into the specialist cancer service, as required. This should reassure patients that they are able to re-access appropriate, named support quickly should they need it, without having to go via their GP.

The three groups who will be first to look at the potential implementation of supported self-management for their patients at UCLH will be the lymphoma, breast and prostate teams. Work is already underway within these groups to establish stratification criteria and newly-designed follow-up pathways, which will then be subjected to rigorous pilot testing and evaluation by service users before any wider implementation.

6.1 Evaluation and research

The Macmillan Support and Information Service at UCLH is a new service with an agreed priority to develop supportive care research. The service is staffed by a multi-professional team who appreciate the need to innovate, evaluate and research in order to improve patient’s experience of cancer, its treatment and recovery.

Our aim is to identify new interventions to support and enable people with cancer and their families, and research and evaluate their effectiveness.

The service as a whole is designed to reflect Macmillan Cancer Support’s nine outcomes and incorporates, within our emerging programme, many initiatives implemented or sponsored by Macmillan; electronic Holistic Need Assessment, wellbeing clinics, recovery workshops, H.O.P.E Programme, Schwartz Rounds and Sage and Thyme. The service was established with the view to becoming a ‘learning laboratory’. All facets of the service are evaluated and we respond to this as an ongoing process. In particular, we have recently designed a bespoke survey for visitors to the Living Room to understand their experience in more depth.

Our ambition is to develop a platform which allows us to further identify innovative interventions and undertake credible research to evaluate their effectiveness. We aim to design interventions to improve patient experience, symptoms and side effects of treatment, and enhance self-management of recovery.
We are currently in the process of defining our key research priorities in line with our own strategic and national strategic priorities. We are also strengthening and clarifying our academic links. From this we hope to develop our own model of clinical/academic research and development in supportive cancer care.

Our long-term vision is to create a UCLH-Macmillan Centre for Supportive Cancer Care Research.

7. Funding and fundraising
The Macmillan Support and Information Service is currently funded by the NHS and University College Hospital Cancer Fund. Whilst UCLH and Macmillan Cancer Support are continuing to work together to continuously improve cancer care and support, the initial funding that Macmillan provided has now been utilised. To ensure that we can continue to develop and expand our services, the UCH Cancer Fund has been established to help raise the funds to achieve our ambitions.

University College Hospital Cancer Fund
University College Hospital aims to ensure that all people with cancer, their families and carers receive a world-class service, from diagnosis through treatment and beyond. The University College Hospital Cancer Fund has been created to support important areas of this work beyond what the NHS is able to provide. This includes the essential funding for the Macmillan Support and Information Service.

8. Our plans for the future
Having seen the positive impact our service has had on patients and families over the last two years it is our ambition that we will:

• Extend our reach further to more cancer patients and their families at UCLH
• Work with the clinical teams and primary care colleagues to ensure that the services offered in the centre are integrated as a part of routine care
• Be recognised nationally and internationally as a leading service in the provision of individually-tailored cancer support
• Increase and ensure more sustainable levels of income to fund future growth and ensure financial stability.

2014/15 is an important year for us. We will be consolidating our achievements of the last two years and preparing for the next stage in our development. We will be raising awareness and understanding of what the service offers and building a platform for further growth.

Our thanks
Our first two years have been about building the service, building our team and developing what we do in response to the needs of patients, families and the clinical teams who care for them. Our vision, inspiration and motivation are rooted in ensuring that we respond to these needs in a way that provides the highest quality service and maximises our precious resources. None of this could be achieved without the outstanding teamwork exemplified by our team and also the tremendous support we have had from patients, their families, staff at UCLH, the expertise from Macmillan Cancer Support and our colleagues in the UCH Cancer Fund.