

Maggie's Evidence-based Programme

maggie's

“ The groundbreaking model of cancer support pioneered by Maggie’s has been developed to meet the practical, emotional and social needs of people with cancer. With new diagnoses rising by 3% each year there is a growing need for Maggie’s Centres and the evidence-based support they offer people during diagnosis, treatment and survivorship. ”

Sean Duffy
National Clinical Director for Cancer, England

Maggie’s Centres

As Chairman of Maggie’s Professional Advisory Board I am pleased to introduce this Medical Brief which provides an outline of Maggie’s programme of cancer support. All the elements of our programme have been chosen on the basis of evidence of their effectiveness in meeting the needs of people affected by cancer.

The Professional Advisory Board, which includes eminent clinicians and other healthcare related professionals, plays a key role in supporting our Centres to deliver Maggie’s programme in a coherent and consistent manner. It also evaluates the delivery and development of the programme and advises on the implementation of recommendations from programme reviews and audits, ensuring that the programme is effective and of a high quality across our network of Centres.

Professor Bob Leonard
Chair of Maggie’s Professional Advisory Board

What is Maggie's

Since 1996, Maggie's has been pioneering a new concept of cancer support in the UK. We provide practical, emotional and social support to people with cancer, their family and friends. Built in the grounds of specialist NHS cancer hospitals, our Centres are warm and welcoming places, with qualified staff offering an evidence-based core programme of support developed to complement medical treatment.

How we started

A diagnosis of cancer hits you like a punch in the stomach. These are the words of Maggie Keswick Jencks, our co-founder with her husband Charles Jencks, who was diagnosed with breast cancer in 1988. During her treatment process and the challenges it brought, Maggie formulated a vision of a cancer support Centre that could make the experience of diagnosis and treatment easier to bear.

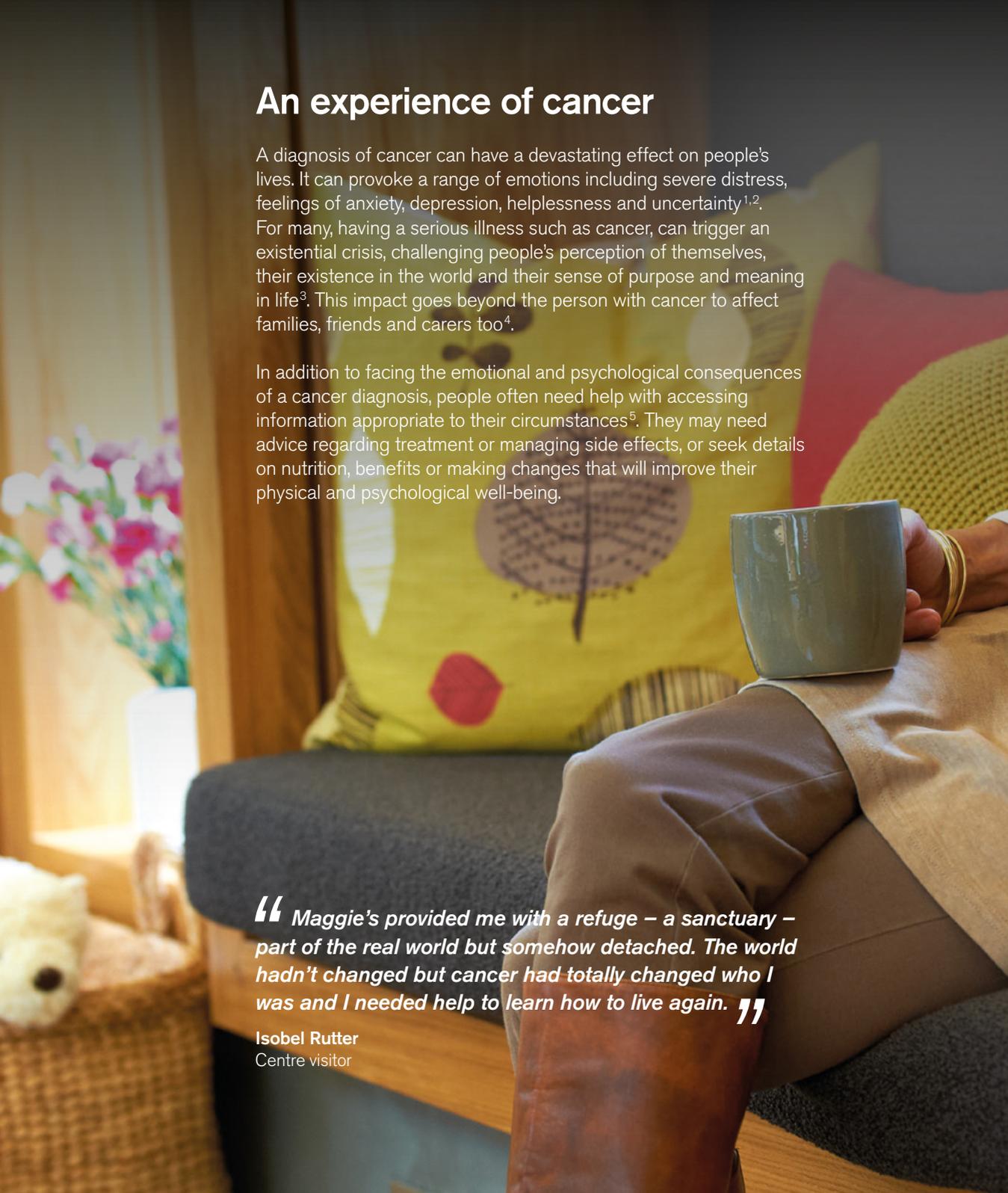
Maggie believed professional, emotional and psychological support could change the way people lived with cancer. She felt that people should be encouraged to become active participants in their treatment and to take control of the process where they could. Her key idea was to bring people together, in a place which would help them to find comfort in the experiences of others and where they could be provided with structured information and professional support.

Supported by her oncology team, including Professor Bob Leonard and nurse Laura Lee, Maggie's vision became a reality in 1996 with the opening of the first Maggie's Centre in Edinburgh. There are now eighteen Centres across the UK, online and abroad, with more planned for the future.

An experience of cancer

A diagnosis of cancer can have a devastating effect on people's lives. It can provoke a range of emotions including severe distress, feelings of anxiety, depression, helplessness and uncertainty^{1,2}. For many, having a serious illness such as cancer, can trigger an existential crisis, challenging people's perception of themselves, their existence in the world and their sense of purpose and meaning in life³. This impact goes beyond the person with cancer to affect families, friends and carers too⁴.

In addition to facing the emotional and psychological consequences of a cancer diagnosis, people often need help with accessing information appropriate to their circumstances⁵. They may need advice regarding treatment or managing side effects, or seek details on nutrition, benefits or making changes that will improve their physical and psychological well-being.



“ Maggie's provided me with a refuge – a sanctuary – part of the real world but somehow detached. The world hadn't changed but cancer had totally changed who I was and I needed help to learn how to live again. ”

Isobel Rutter
Centre visitor

Complementing NHS services

Since our inception we have worked alongside the NHS as a partner in pioneering effective cancer care. We have close working relationships with our partner hospitals and approximately 50% of Maggie's visitors are referred to a Centre by their doctor or nurse.

Our focus on psychological support and clear information for all cancer patients links into the NHS's ongoing implementation of improved care. The Government's Cancer Reform Strategy (2007) also points to the need to support and empower people through and beyond their cancer journey and uses Maggie's as a case study, recognising us as a leading provider of this kind of support.

Over two million people in the UK are now living with cancer⁶. Survival rates for many of the most common cancers have improved considerably in the last decade⁷ and the number of survivors is likely to increase by over 3% per year⁸. This means we now have a larger percentage of the population potentially in need of what we offer.

Maggie's programme of support

Maggie's Centres welcome people with cancer, their family and friends, at any point in the cancer experience: diagnosis, treatment, post-treatment, recurrence, end of life and bereavement.

Anyone can drop in to a Centre whenever they want. Our programme is free of charge, with no referral or appointment required and people can access our support for as long as they need it.

Every visitor has access to our cancer professionals and to our core programme of support which encompasses practical information, psychological and emotional support, stress and distress management and help to make choices to live differently.

We work with each individual to identify their needs, and elicit their concerns and fears. Understanding each individual's circumstances is central to what we do and allows us to guide each person through aspects of the programme most appropriate to them.

The Maggie's programme is evaluated regularly, in line with evidence-based practice and informed by external research findings, and by drawing on advice gained from our external reviews.

Details of our programme

Accessing and understanding information

It is known that people affected by cancer have varying informational needs^{9,10,11}. The provision of information and support in understanding the information about their cancer has been demonstrated to be a key element in decreasing anxiety and uncertainty and regaining a sense of control¹². The aim at Maggie's is to help people find and understand the relevant information for their particular situation. We do not give advice regarding individual treatment plans but provide support to clarify people's understanding and to formulate questions, which they can take back to their healthcare team.

Although people receive excellent information directly from their healthcare team, many people fail to recall the information given in a consultation with medical staff¹³, so additional help here can be necessary. Every Maggie's has a library and utilises information provided by other cancer charities such as Macmillan and Cancerbackup, Breast Cancer Care and Cancer Research UK. At each Centre, visitors are provided with an opportunity to request and discuss information at a pace that is tailored to their individual needs. This combination of providing support through information and using it as a vehicle to elicit concerns is a fundamental aspect of Maggie's core programme.

Each Centre also has a Benefits Adviser who is available to support visitors and carers with organising their finances and securing benefits. Disability due to illness can mean that people are unable to work for periods of time and sometimes indefinitely, leading to a reduction or loss of income. Many cancer patients report needing advice on these issues¹³.

Emotional and psychological support

People visiting a Maggie's Centre can find support related to any emotional or psychological difficulty they are experiencing. We provide this support in a flexible way as some people feel more comfortable speaking with a cancer support specialist in the drop-in service, while others may need structured, individual sessions with one of our psychologists.

Underpinning all the services at Maggie's is the opportunity for people to meet others with whom they can identify, either around the kitchen table or in any of the workshops or support groups. To hear personal stories of how others have overcome cancer obstacles can be one of the most powerful means of helping people increase self efficacy and gain confidence that they can take on the challenge of cancer^{14,15}. Participating in a cancer support group can also complement and enhance the supportive relationships a person may have amongst family and friends¹⁶. For those unable to visit a Maggie's Centre, we also host a thriving Online Programme which provides an opportunity for those unwell or living in remote areas to receive professional support as well as encouragement from other members of the Maggie's community.

In addition to opportunities to meet other people with cancer, their family or friends, Maggie's provides groups and courses aimed at addressing the unique needs of patients and carers throughout the cancer experience¹⁷. From our pre-treatment workshop, 'Getting Started with Cancer Treatment', to the post-treatment course, 'Where Now?', Maggie's provides a range of psycho-educational and supportive opportunities for cancer patients and their loved ones to take charge of their well-being and feel a part of looking after their health.

Some individuals may require more individualised support. Prevalence rates estimate that over one-third of cancer patients experience heightened levels of distress^{18,19}. However, the majority of these go undetected and untreated²⁰ and may interfere with patient satisfaction with care, treatment compliance²¹ and quality of life²². To respond to this potentially heightened need for individualised care, each Maggie's Centre has a Clinical Psychologist accessible by both self and professional referral.

Living well

Experiencing a serious illness such as cancer can lead people to reflect deeply on how they have been living their lives. A 'teachable moment' can occur here, where people find themselves motivated to adopt healthy behaviour patterns^{23,24}. At Maggie's, we have the facilities, support and knowledge to help people capitalise on this enthusiasm. This can optimise their physical, emotional and psychological health, enabling them to cope as best they can with their experience. These changes can be applied to nutrition, exercise, stress management and other lifestyle factors.

Diet and nutrition

Patterns of diet and nutrition can be linked with the incidence of cancer²⁵, with poor diet considered to be the second largest risk factor after smoking. It may be responsible for up to one-third of all cancer deaths²⁶. Our Centres offer nutrition courses and workshops which inform and support our visitors in making nutritional choices that can modify the risk of cancer recurrence, off-set the side effects of treatment and improve their physical and psychological well-being.

Physical activity

The evidence base for the benefits of physical fitness programmes is growing, with a number of studies affirming the effects of exercise on managing side effects and increasing vitality^{27,28,29}. Maggie's supports people to incorporate physical activities into their lifestyle through the opportunity to take part in t'ai chi, yoga, fatigue management workshops, courses and group or individual psychological sessions to build the confidence to take exercise again.

Stress management and relaxation

To support patients and their family and friends in reducing their levels of distress and increasing their sense of well-being at all stages of the cancer experience, Maggie's offers cognitive behavioural and mindfulness-based stress-reduction courses. During these courses, participants have the opportunity to learn and practise coping skills empirically demonstrated to contribute to reducing distress, improving sleep, and increasing quality of life^{30,31,32,33,34}. Drop-in relaxation, meditation, and mindfulness courses also provide an opportunity for people to continue to develop and practise these skills.

Environment

Maggie's Centres are unique physical environments, designed by some of the most significant and original architects in the world. All are built with certain fundamental themes in mind and an appreciation of how environment can affect wellbeing^{35, 36, 37, 38, 39}. They are spaces that feel warm and supportive whilst also being stimulating and intriguing. They help to inspire people to explore the things they can do to help themselves to live with, through and beyond cancer in their lives.

Each building has been designed to accommodate the full breadth of our programme, keeping everything under one roof. At the same time, they are domestic in scale, with a kitchen at the Centre to facilitate social interaction and a sense of community. The interiors are comfortable and home like but also aesthetically sophisticated, conveying the value we place on therapeutic environments and our aim to make people feel better simply by being inside a Centre.

As Charles Jencks, landscape architect, writer and husband of Maggie, writes in his recent book *The Architecture of Hope*, 'For cancer sufferers, the architecture acknowledges their plight and affirms their worth'.

Open Centres

Edinburgh 1996
Glasgow (Gatehouse) 2002
Dundee 2003
Highlands 2005
Fife 2006
West London 2008
Online 2008
Cheltenham 2010
Glasgow (Gartnavel) 2011
Nottingham 2011
South West Wales 2011
Hong Kong 2013
Newcastle 2013
Aberdeen 2013
Lanarkshire 2014
Oxford 2014

Interim services

Wallace (Cambridge)
Merseyside at the Clatterbridge

In development

Forth Valley
Manchester (The Christie)
North East London (St Bartholomew's)
Oldham
Southampton
South East Wales
South West London (The Royal Marsden)
Yorkshire





“ Good medicine necessitates scientific and technical excellence. It also demands engagement with patients as individual human beings with unique values, fears and hopes. Patient care is much more than the treatment of disease; it requires human understanding. Maggie’s contributes hugely to the human side of cancer care and by working in partnership with NHS oncology units ensures that the whole patient is supported. They do this both through the programme of support and through the Centres themselves – the effect of a patient’s environment on their wellbeing should not be underestimated. ”

Dr Sam Guglani

Consultant Oncologist, Cheltenham General Hospital

“ I have seen the work of Maggie’s Centres first hand and was impressed by the quality of emotional and psychological support they provide to cancer patients and their families. A patients support network makes a real difference to their health outcomes and I can’t speak highly enough about the evidence-based programme of support offered at every Maggie’s Centre both in the UK and in their growing international presence. ”

Professor the Lord Denzi of Denham

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Please note: Reference update planned.

“ As an oncologist I know that no one underestimates the difficulties involved in receiving the news that one has cancer. The emotional trauma can be just as difficult as the physical effect. Maggie’s Centres help in a way that is a natural extension of our clinical work. For our cancer patients what Maggie’s does is vital. ”

Professor Bob Leonard
Chair of Maggie’s Professional Advisory Board

www.maggiescentres.org

Maggie’s Keswick Jencks Cancer Caring Trust (Maggie’s) is a registered charity, No. SC024414