

A person wearing a yellow and black plaid shirt is holding a camera up to their eye, as if taking a photo. The background is a warm, golden-yellow, out-of-focus scene. A blue, semi-transparent geometric shape, resembling a stylized house or a camera lens, is overlaid on the person's chest and the camera. The word "MAGGIE'S" is written in a white, hand-drawn, sans-serif font across the lower half of the image.

# MAGGIE'S

February 2019



*maggie's*





# Assumptions?



# Assumptions

A charity, run by volunteers

Health professional team

Governance

Holistic programme of psychosocial care

Aligned with best available external evidence

Integrated with NHS and Social care

Affluent women with breast cancer

Cross-section of cancer sites and social demographics

Responding to co-morbidity and aging population

Always finding creative routes to facilitate access



# Assumptions

Just the person with cancer

Family  
Employer  
Colleagues  
Friends

A hospice

Care throughout the cancer experience  
Across primary and secondary care  
Responding to enduring impact of cancer treatments  
When bereaved







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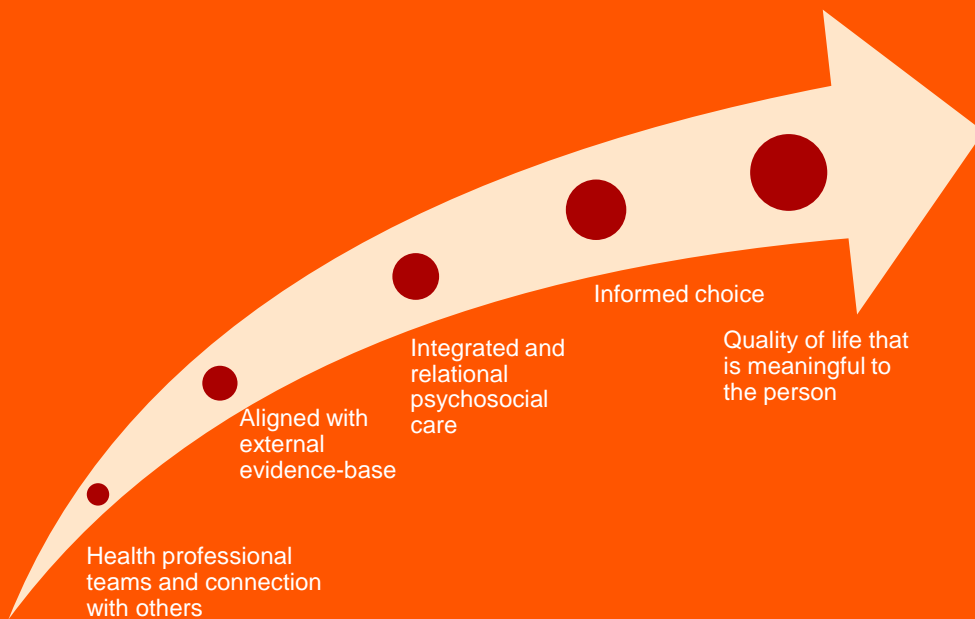


# Psychosocial care at work?

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Each person chooses their own unique pathway to a quality of life that is meaningful for them





# Our staff and programme

## Staff team

- Cancer support specialists: with professional backgrounds in oncology nursing, Therapeutic radiotherapy, Pharmacy
- Clinical or Counselling Psychologist
- Benefits advisor

## Programme

- Information and emotional support
- Courses and workshops (for example)
  - Getting started
  - Nutrition
  - Where Now?
  - Managing Stress
- Psychological support (NICE levels 1-4)
- Facilitated support groups
- ***Working with others***
  - NHS colleagues
  - Charity colleagues





# Our Centre's in numbers

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# Maggie's working- Activity 2018

Visits from:

281,310

Total Visits

148,057

People with cancer

162,444

Women

84,948

Men

133,252

67,065

Family, friends and Carers

People with a new cancer diagnosis

# Maggie's Activity 2018

15% Breast

13% Prostate

7% Urological

12% Lower GI

6% Gynecological

4% Skin

13% Lung

3% Head and Neck

1% Testicular

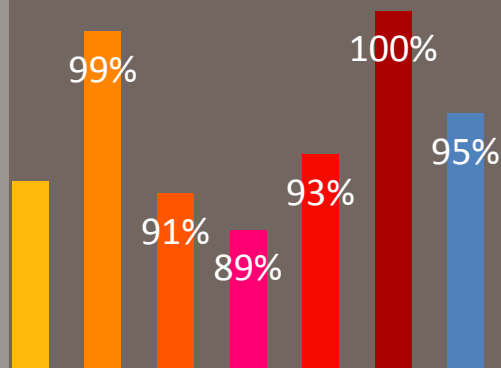
4% Hematological

3% Brain/ CNS



# Maggie's is working

- Felt Maggie's was meeting their cancer support needs.
- Found every aspect of support offered at Maggie's helpful or very helpful
- Understanding of cancer improved
- Reported an improvement in their ability to manage the stress
- Felt less alone after visiting Maggie's
- Had a positive experience at Maggie's
- Found every aspect of support offered at Maggie's helpful or very helpful
- 



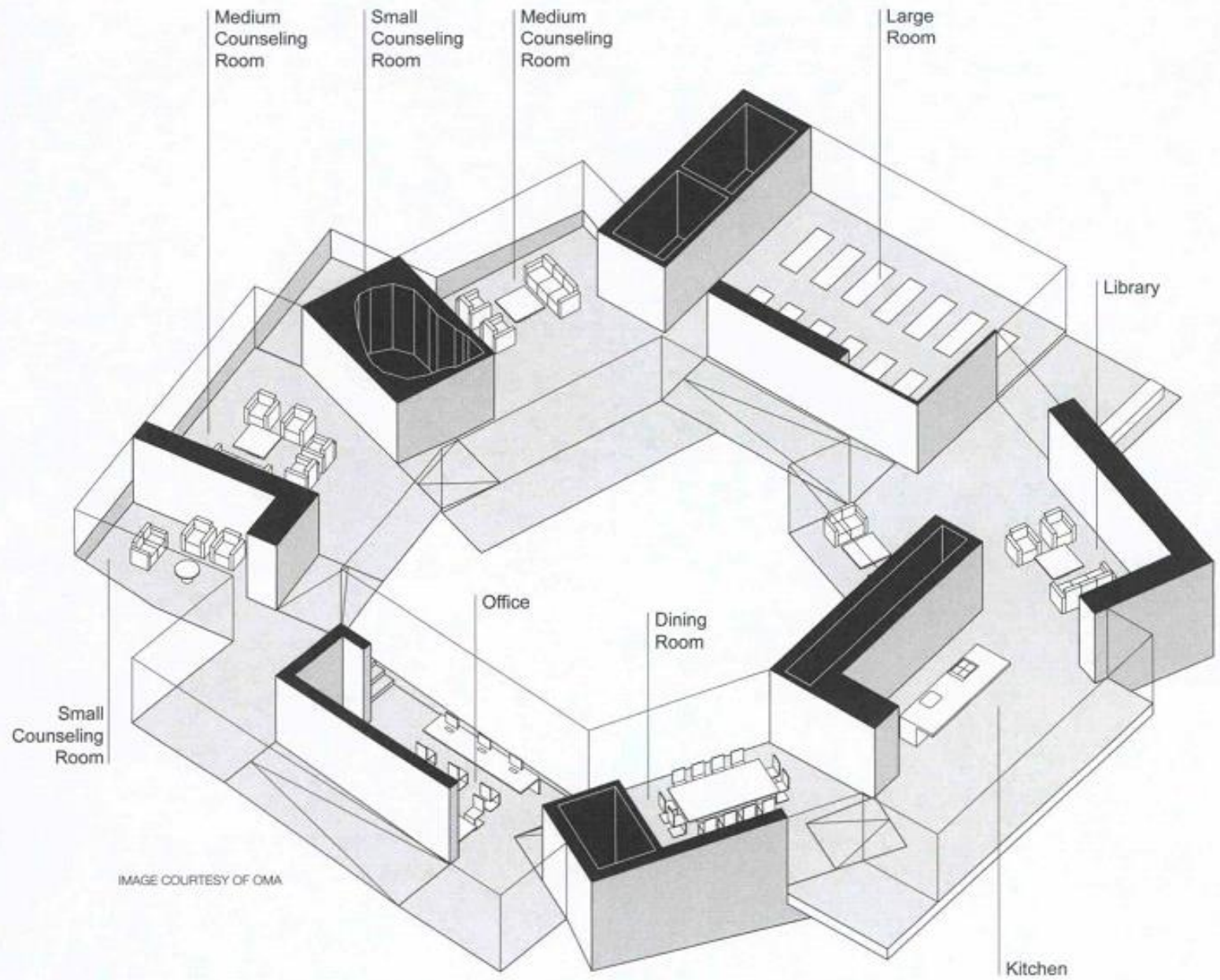
# By the end of 2019 we will support:

	New diagnosis target supported by Maggie's 2019	New diagnosis national	% new diagnosis supported
UK	37,644	360,000	10%
Scotland	10,620	31,331	34%
England	25,728	306,211	8%
Wales	1,700	19,088	9%





# Why the emphasis on environment?



**Above** - A sequence of rooms superimposed one upon the other negates the need for hallways














“Neither neutral or  
nondescript but  
emotionally resonant”,  
prompting evocative  
memories, memories that  
cultivate resilience.



“Between stimulus and response  
there is a space. In that space is  
our power to choose our response.  
In our response lies our freedom  
and growth.”

Viktor Frankl (attributed)



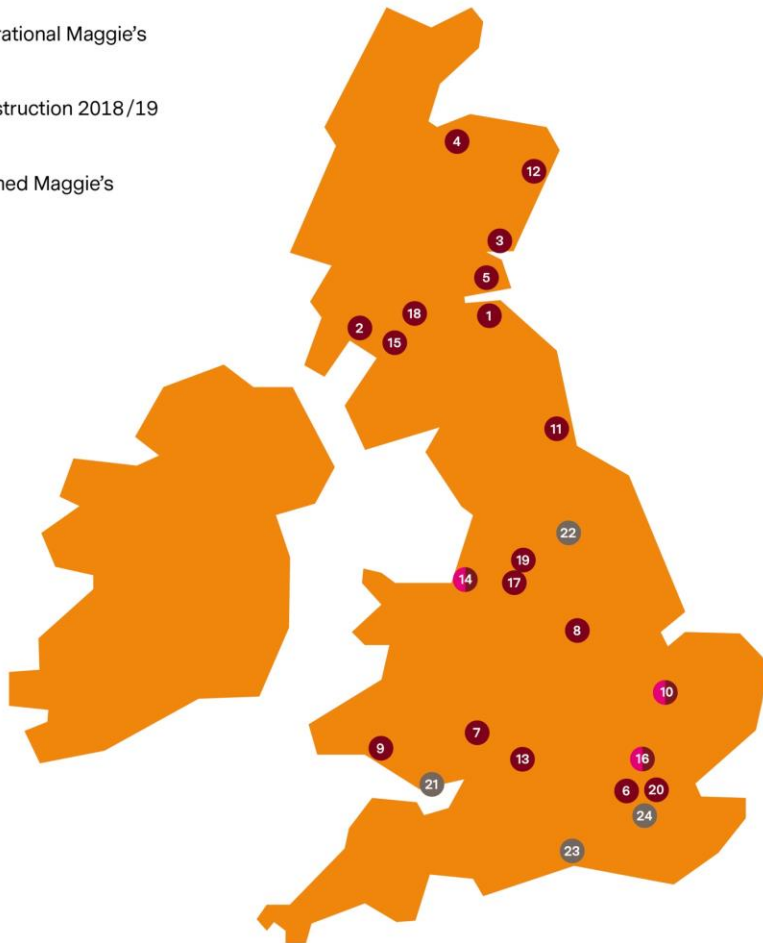


# Our Centre's

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# Maggie's centre locations

- Operational Maggie's
- Construction 2018/19
- Planned Maggie's



EUROPE



MIDDLE EAST AND ASIA

## Maggie's Centres

- 1 Edinburgh
- 2 Glasgow, Gartnavel
- 3 Dundee
- 4 Highlands
- 5 Fife
- 6 West London
- 7 Cheltenham
- 8 Nottingham
- 9 Swansea
- 10 Cambridge (interim)
- 11 Newcastle
- 12 Aberdeen
- 13 Oxford
- 14 Merseyside (interim)
- 15 Lanarkshire
- 16 Royal Free (interim)
- 17 Manchester
- 18 Forth Valley
- 19 Oldham
- 20 Barts

## Centres in Development

- 21 Cardiff
- 22 Leeds
- 23 Southampton
- 24 The Royal Marsden
- 25 Northampton
- 26 Taunton
- 27 Coventry

## International Centres

- 37 Hong Kong
- 38 Tokyo
- 39 Barcelona
- 40 Norway
- 41 Netherlands









# Fourstories

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# Research & relationships

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# Our research priorities

- Demonstrate the impact of our existing programme and developments in the programme
- Facilitate access to our programme of psychosocial cancer support
- Understand the impact of Maggie's environments

Able to generalise outcomes to wider cancer care community

Aligned with NCRI Living with and beyond priorities





# NCRI Research Priorities

As you are aware:

People living with and after cancer played pivotal role in an extensive consultation

Will influence future research direction and funding decisions

Priorities reflect longstanding contribution Maggie's already makes to cancer care

Future research collaborations will not only address our existing priorities but be aligned with the new NCRI priorities.

## UK Top 10 living with and beyond cancer research priorities\*

1. What are the best **models for delivering long-term cancer care** including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?
2. How can patients and carers be **appropriately informed** of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?
3. How can care be better co-ordinated for people living with and beyond cancer who have **complex needs** (with more than one health problem or receiving care from more than one specialty)?
4. What causes **fatigue** in people living with and beyond cancer and what are the best ways to manage it?
5. What are the short-term and long-term **psychological impacts** of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?
6. How can the **short-term, long-term and late effects** of cancer treatments be (a) prevented, and/or (b) best treated/ managed?
7. What are the **biological bases of side-effects** of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?
8. What are the best ways to manage **persistent pain** caused by cancer or cancer treatments?
9. What specific **lifestyle changes** (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?
10. How can we **predict** which people living with and beyond cancer will experience **long-term side-effects** (side-effects which last for years after treatment) and which people will experience **late effects** (side-effects which do not appear until years after treatment)?

\*Priorities relate to adults living with and beyond cancer



# OvPsych2

Randomised controlled trial to evaluate the impact of psychological support for women after treatment for ovarian cancer

- Collaboration with Oxford University and Imperial College
- Eight Maggie's centres participated
- Central aim to help women take a fresh look at how they wish to live their life post treatment.
- Psychological approach typical of other aspects of the Maggie's programme
- Example of Maggie's working alongside colleagues in local Clinical Trials Unit and Gynae MDT.
- Fear of progression reduced for women receiving psychological support
- Depression reduced over time for all participants
- Next step – reflect and use the findings within Maggie's and share learning with NHS colleagues.



## Impact of value co-creation on the wellbeing of men with cancer

- Collaboration with University of Edinburgh Business School.
- Study in final stages.
- Examples of Value Co-creation at Maggie's include men gathering together as a Prostate Cancer Support Group or a Men's Groups to seek information and share experiences.
- Early Questionnaire findings (n=213) show all four dimensions of wellbeing enhanced by value co-creation activities – psychological, social, existential and physical.
- Early qualitative findings indicate increased confidence in communicating about their illness, finding meaning in their life and the motivation to 'live well' despite their illness.





## Quotes from value co-creation study interviews

*“I suppose I am a typical man, I sort of tend to keep all these things to myself. You find it hard to talk about it. But, I have got to admit, since I’ve been coming here, I do find a lot easier, you know, in everyday life to talk about these things than I did previously. It has been a benefit, really.”*

*“I think the main thing, when you come here and talk to other people, is you get their progress report and some insights. It’s encouraging, isn’t it? It gives you an aim, a goal to strive for or whatever.”*



## Impact of “Where Now?”

- Collaboration with University of Aberdeen Health Psychology Masters programme.
- Rolling evaluation of the ‘Where Now?’ course at a sample of six Maggie’s Centres across the UK.
- Where Now? is our course designed to help people improve all dimensions of their quality of life post treatment.
- It is part of our core programme in all centres.
- Current findings highlight, in particular, how the course helps people feel more confident in their ability to undertake physical activity.
- Also, the importance of open discussion with people who are non-judgemental, don’t make assumptions and are at a similar stage in their cancer experience.





## Exploring changes in psychosocial care needs, programme choice and the role of the Cancer Support Specialist.

- Collaboration with University of Chester Applied Psychology Masters programme.
- Four Maggie's centres will participate over the next six months.

People with cancer and people caring for someone with cancer, who agree to take part:

- Will have their interaction with the CSS and programme choice discretely recorded.
- Will be invited to complete questionnaires on Quality of Life, Unmet psychosocial care needs, Emotional wellbeing and Psychological Flexibility over a six week period.



A still life photograph of a wooden table with a dark, angular geometric overlay. Two blue glass cups are positioned on the left, and a clear glass vase with pink flowers is on the right. The text "Thank you" is centered in white.

Thank  
you

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# Questions?

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