

**MACMILLAN  
CANCER SUPPORT**



CANCER  
RESEARCH UK  
FACILITATORS

**NHS**

**Bristol, North Somerset  
and South Gloucestershire**  
Clinical Commissioning Group

# Social prescribing: navigating patients from cancer prevention to life after treatment

A series of lunchtime webinars for social prescribers

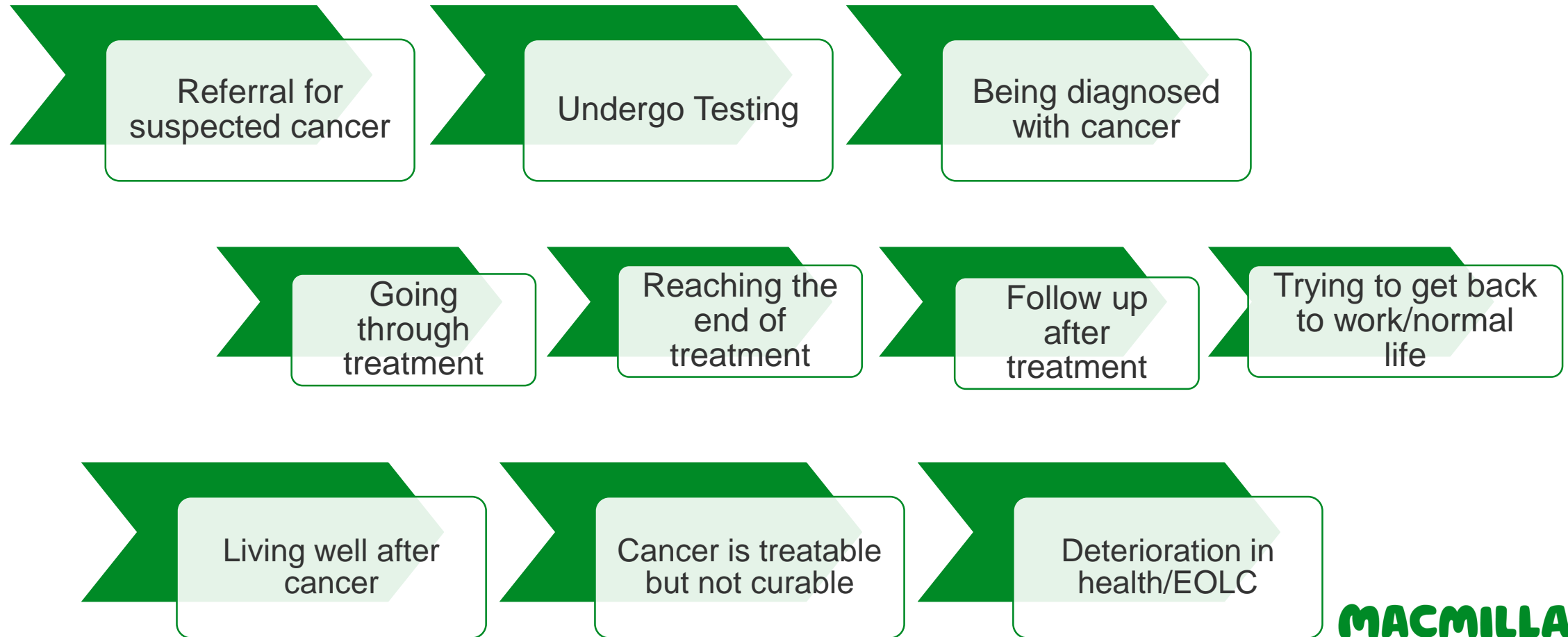
# Sessions

- **Cancer as a Long-Term Condition**
  - Thursday 17<sup>th</sup> September 12.30-13.30
  - Dr Glenda Beard Macmillan GP BNSSG
- **Overview of Cancer prevention and Cancer screening**
  - Thursday the 24<sup>th</sup> September 12.30-13.30
  - Christine Nagle & Debs Jones, CRUK Facilitator Programme
- **The Journey from Treatment and Beyond**
  - Thursday the 1<sup>st</sup> October 12.30-13.30
  - Helen Shallcross, Macmillan Cancer Rehabilitation/Personalised Care and Support Lead for Somerset, Wiltshire, Avon & Gloucestershire

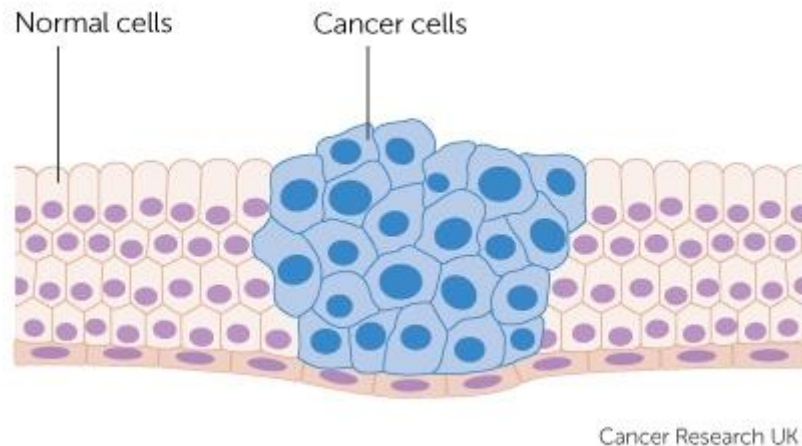
To register for the upcoming webinars please [click here](#)

# The cancer 'journey'

# Different stages of a cancer journey



# What is cancer....?



- Cancer is when abnormal cells divide in an uncontrolled way
- The cells start to grow and multiply too much
- A primary tumour is the name for where the cancer starts
- Some cancers can spread to other areas of the body, these are secondary tumours of metastasis

# Many cancers can be cured but sometimes they come back

- This could be because the first treatment didn't get rid of all of the cancer cells and those left behind start to grow a new tumour
- Or because some cancer cells have spread elsewhere in the body and started growing there to form a tumour

# How is Cancer diagnosed

- There are more than 200 different types of cancer that can cause many different symptoms
- Patients may be diagnosed with cancer in lots of different ways such as
  - Screening eg cervix, breast, colorectal
  - Symptoms
  - Incidental findings

# Cancer Treatment

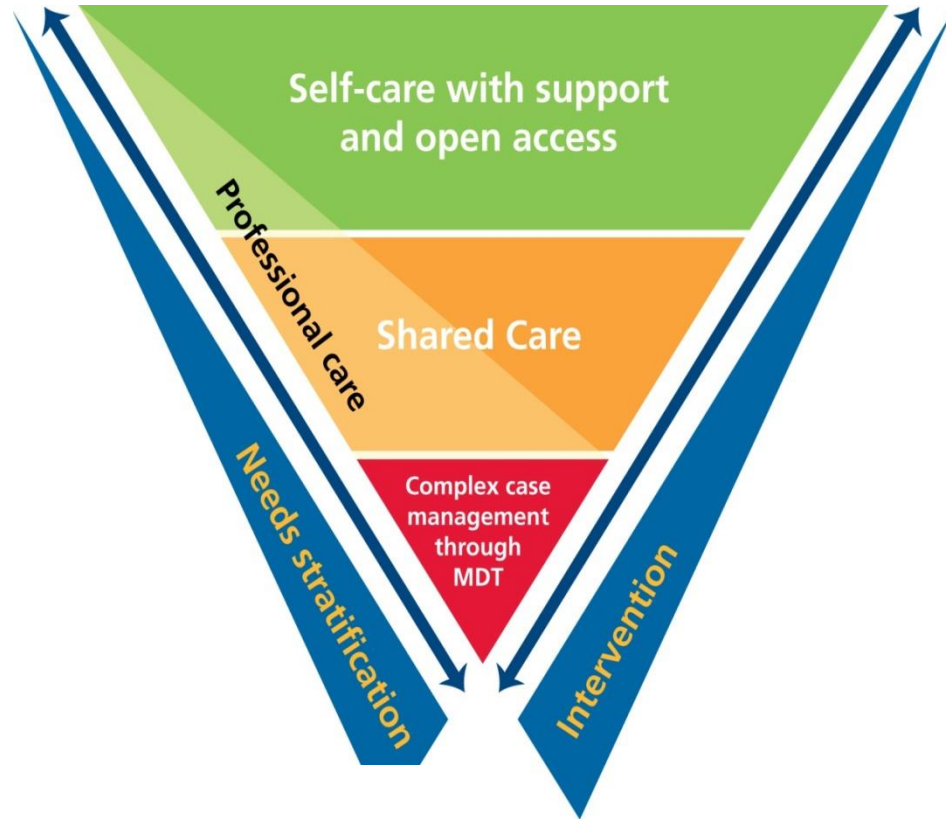
- Cancer treatment is decided by a team of specialists together with the patient and depends on the where the cancer is, how big it is, whether it has spread, and the patients general health
- Some cancers do not need active treatment and patients are monitored to make sure their cancer is not growing or spreading
- Surgery
- Chemotherapy; is the use of anti cancer drugs to destroy cancer cells
- Radiotherapy; means the use of radiation, usually x-rays, to kill cancer cells
- And others.....



# After Cancer Treatment

- The follow up offered to patients depends on the cancer and the treatment the patient has received
- It can involve blood tests, scans and other investigations
- It might mean patients have to attend the hospital or that they can be managed at home by their GP
- The amount of follow up usually decreases as time passes after treatment has finished.

# Risk Stratified Model of Care



Risk Stratified Model of Care

- Project management
- Clinician engagement
- Patient support
- Remote surveillance

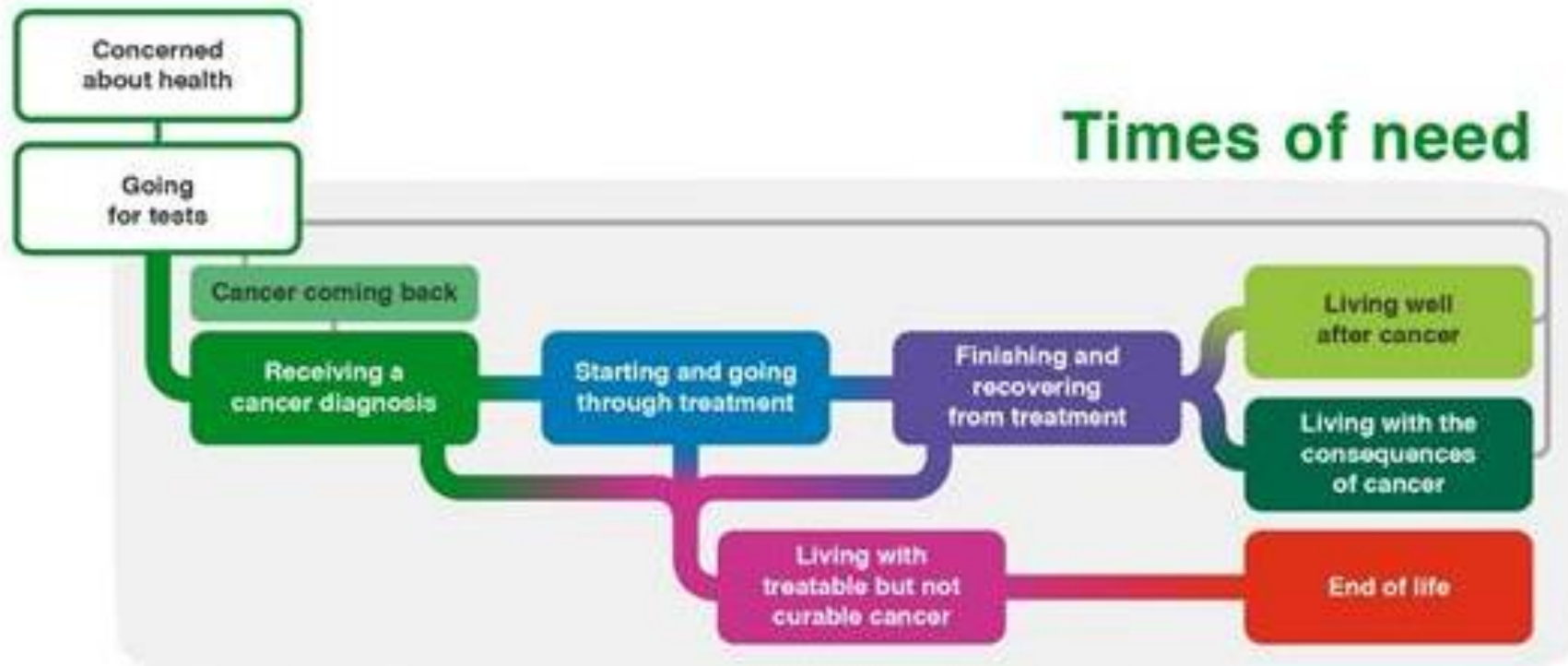


# Stratified follow-up of people living with cancer – what is it?

- Self-management in a safe & supported manner (patients with lower risk of recurrence and late physical and psychosocial effects)
- Improved patient experience by eliminating anxiety and stress
- Rapid re-entry into the specialist cancer service when needed
- Removal of routine follow-up appointments from the pathway

# What does stratified follow up mean for people living with cancer?

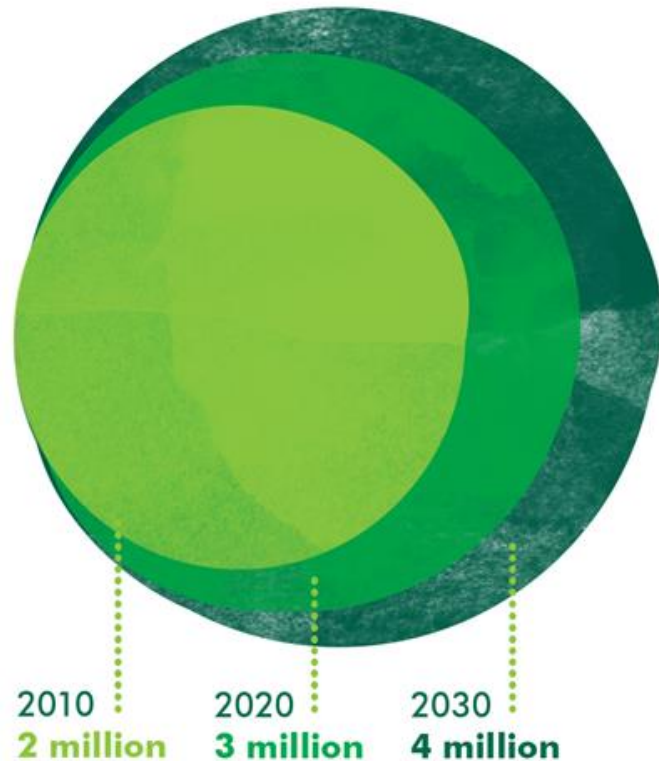
- Support and information for self-management is essential
- Referral for support services such as psychology, return to work, financial advice, managing long-term side effects
- Information sharing –including the person living with cancer and their Primary Care team
- ‘Remote’ monitoring – needs clear understanding of expectations
- Increased need for people to have a clear point of contact in Primary/Community care



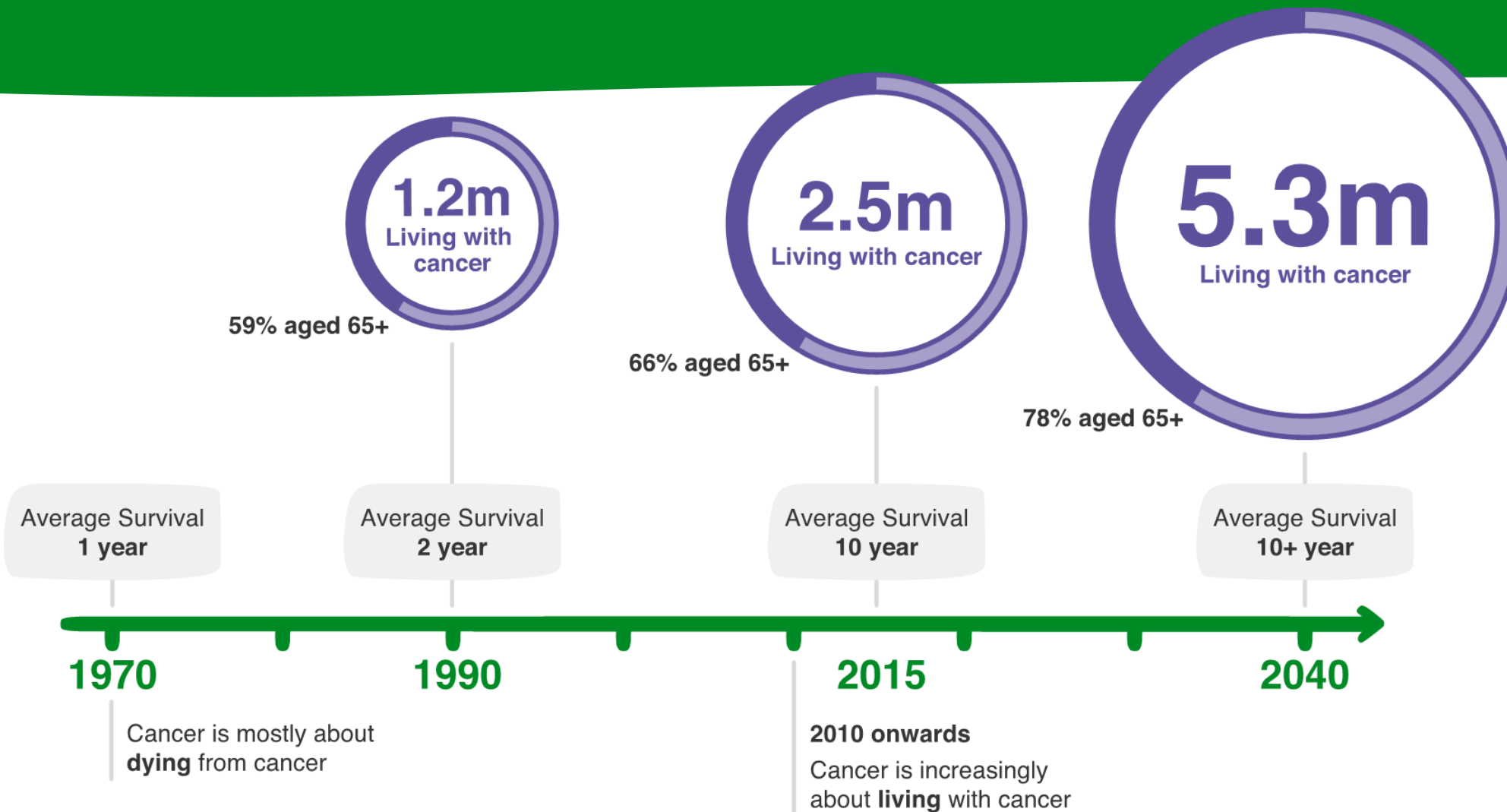
This area accounts for 2.5M people living in the UK that have had a cancer diagnosis at some point in their life (cancer prevalence).

# The Changing Story of Cancer

# What is the estimated number of people living with and beyond cancer in the UK in 2030?

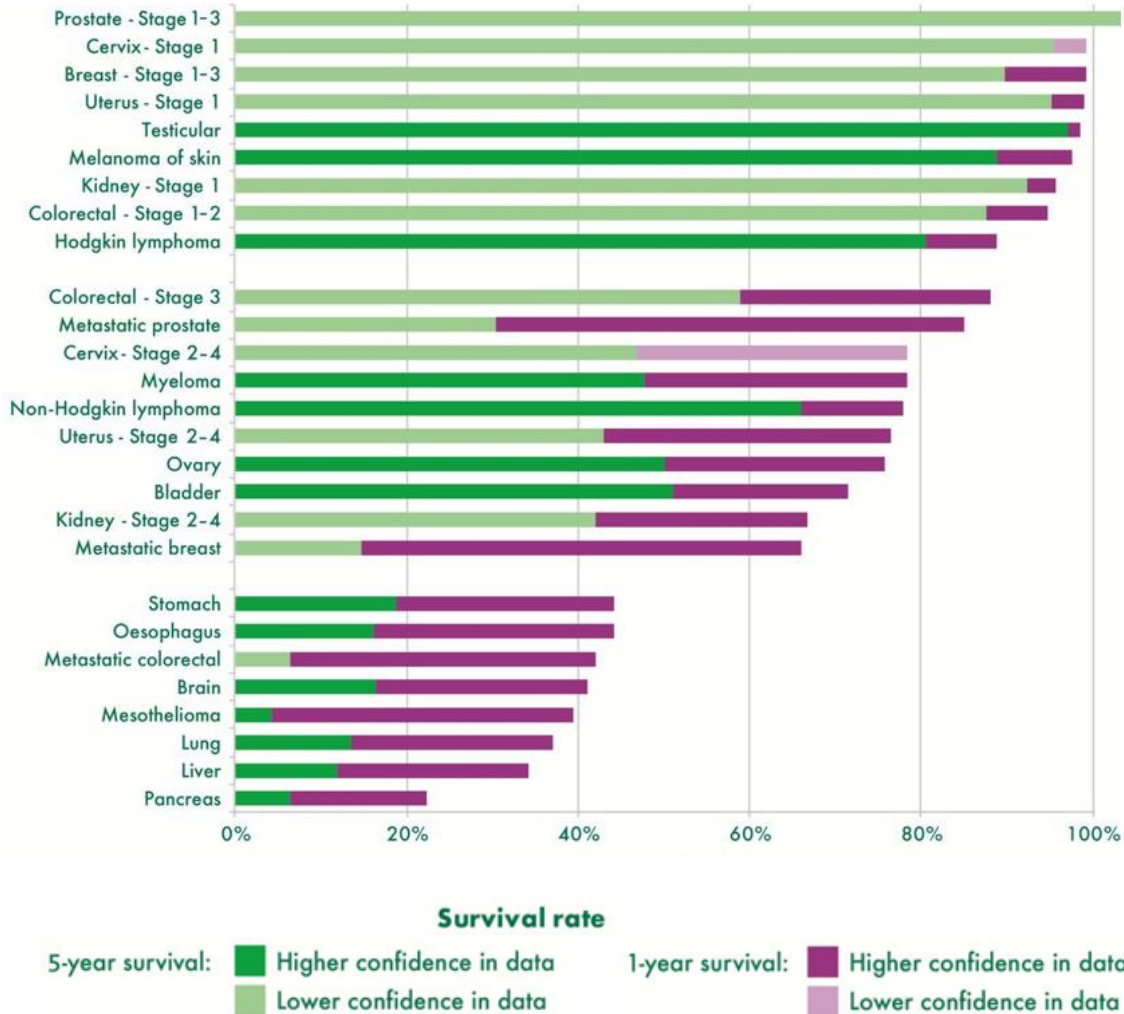


- Improvements in early detection and diagnosis
- More advanced treatments
- Move from acute to long-term condition
- In an average practice of 8000 patients there will be approximately 280 living with and beyond cancer.





# Three cancer groups



**Group 1**  
Many live for more than a decade

**Group 2**  
Most similar to a long-term condition

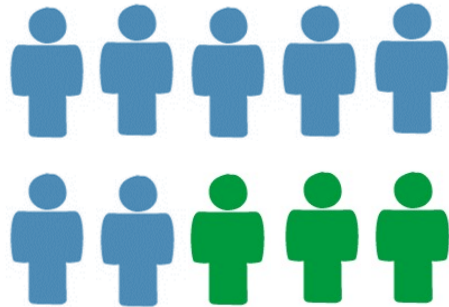
**Group 3**  
Survival for the majority is short term

McConnell, H. White, R. And Maher, J. *Explaining the different complexity, intensity and longevity of broad clinical needs.* 2015.

# How many people living with or beyond cancer experience consequences of treatment that will impact on their life?



At least **1 in 4** of those living with cancer – around **625,000 people** in the UK – face poor health or disability after treatment<sup>1</sup>



**Over 70%** need emotional support<sup>2</sup> – research shows that 2 in 5 people living with cancer are affected by depression, and 1 in 10 experience anxiety<sup>3</sup>



**1 in 5** people living with and beyond cancer may have unmet needs<sup>4</sup>

Care beyond initial treatment predicted to cost the NHS **£1.4 billion a year** by 2020<sup>5</sup>

<sup>1</sup>Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment*. 2013 (1 in 4 people using estimated prevalence of 2.5 million)

<sup>2</sup>Macmillan Cancer Support. *Hidden at Home – The Social Care Need of People Living with Cancer*. 2015.

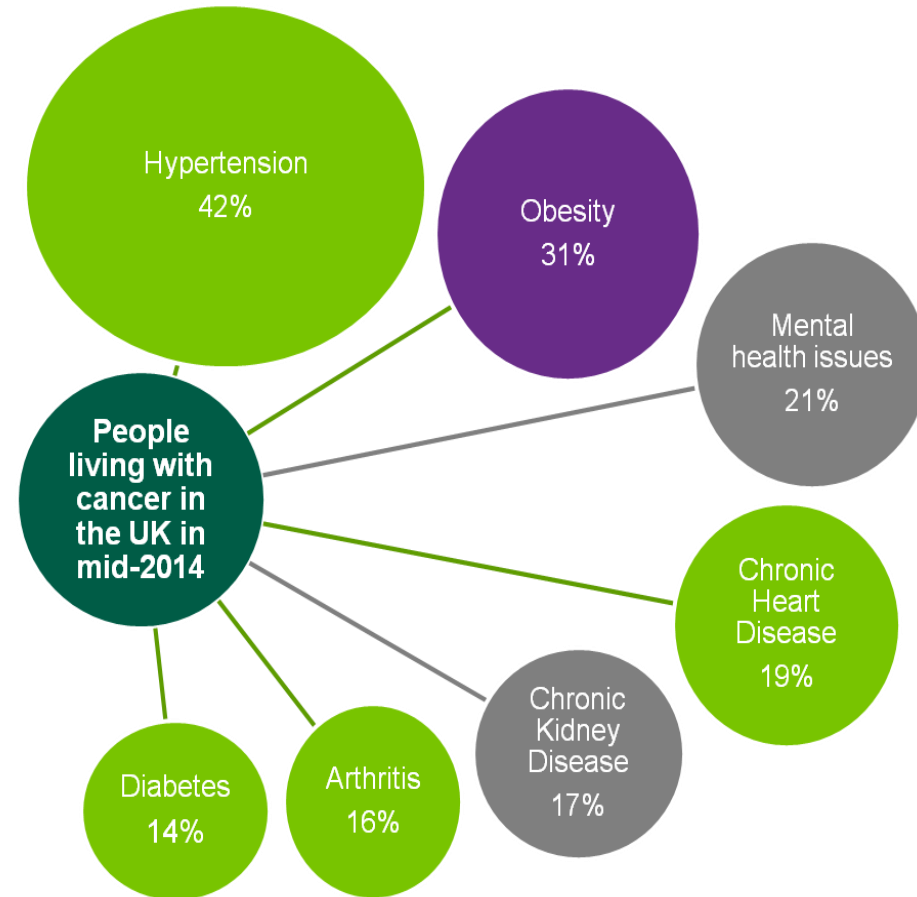
<sup>3</sup>Pitman A, et al. *Depression and anxiety in patients with cancer*. *BMJ* 2018; 361:1415.

<sup>4</sup>Armes J et al. Patients' supportive care needs beyond the end of treatment: A prospective, longitudinal survey. *Journal of Clinical Oncology* 2009. 27:36 6172-6179

<sup>5</sup>Macmillan Cancer Support, *Cancer Cash Crisis*. 2015

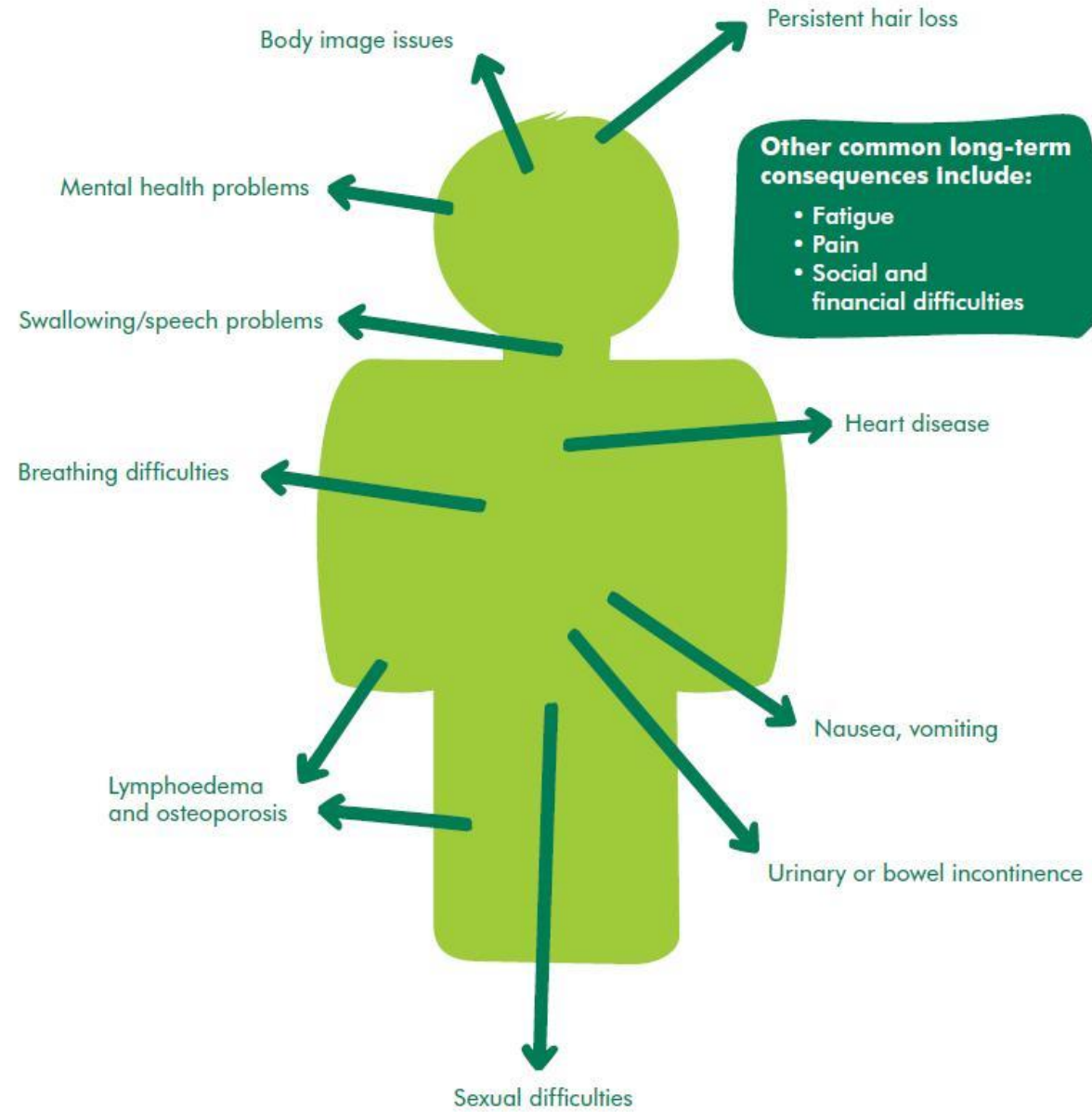
# What proportion of people living with and beyond cancer have another long term condition?

- Over 70% of people living with and beyond cancer have at least one other long term condition



# Treatment Consequences

- Can you name any consequences of treatment?



# Consequences of cancer and its treatment



Around  
**350,000**  
people in England living with  
severe fatigue



Around  
**200,000**  
people living with moderate  
to severe pain after treatment  
to cure their cancer



Around  
**150,000**  
affected by urinary problems  
such as incontinence



Around  
**90,000**  
experiencing gastrointestinal  
problems, including faecal  
incontinence, diarrhoea  
and bleeding<sup>vii</sup>

 One figure =  
10,000 people

**MACMILLAN**  
CANCER SUPPORT



**There is a new story for incurable cancer** - Many people with incurable cancer can live good quality lives with the right support.

**There is a new story for curable cancer** - It is a myth that people who are cured of cancer are therefore well

# We know not everyone is living well



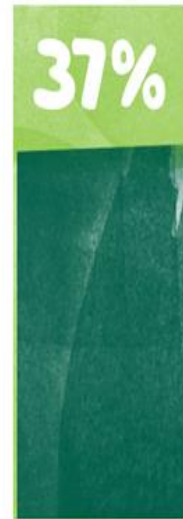
**1 in 4** cancer patients must deal with consequences from their treatments



**1 in 2** cancer patients have co-morbidities



**1 in 5** breast cancer patients face a recurrence of their cancer



People with cancer are **37% more likely to be unemployed** than the general population



More than **one in five (22%)** people living with cancer in the UK – an estimated 400,000 people – **suffer with loneliness** as a result of their cancer.

## Practical and personal needs<sup>vi</sup>

Have needs and get no support at all 10%

Have needs and get support, but not enough 22%

Have needs and get enough support 33%

Do not have any personal or practical needs 36%

## Emotional needs<sup>vii</sup>

25% Have needs and get no support at all

20% Have needs and get support, but not enough

33% Have needs and get enough support

22% Do not have any emotional needs



People with cancer

**Practical tasks** – around **one in three people with cancer (31%)** are either completely unable to do practical tasks such as **prepare and eat food, or do grocery shopping or housework** by themselves, or need a lot of help to do so

**Mobility** – around **one in three people with cancer (32%)** are either completely unable to **get in and out of bed, move around or use transport** by themselves, or need a lot of help to do so

**Personal care** – **one in seven people with cancer (14%)** are either completely unable to carry out personal care routines such as **bathing, dressing or going to the toilet** by themselves, or need a lot of help to do so

**Medical appointments** – more than **one in four people with cancer (27%)** are either completely unable to **travel to medical appointments or pick up prescriptions** by themselves, or need a lot of help to do so

**Looking after dependants** – **one in seven people with cancer (14%)** are either completely unable to **look after their children or other relatives** by themselves, or need a lot of help to do so





# Bromley By Bow Video



# Bromley By Bow Case Studies

## Alex's story



“Before I saw the Macmillan Social Prescribing service I felt lost, I didn't know what to do, who to turn to. It gave me direction”



## Meg's story



“The most important thing about the Macmillan Social Prescribing service was the opportunity to talk to someone who wasn't a family member or friend.”

## Sandra's story



“The Macmillan Social Prescribing service can help you to shrink that bit in your mind that thinks about cancer so you can think about your life”.

*Sandra is a retired breast cancer survivor who lives in Tower Hamlets. She had four 1:1 sessions over the course of a year at the Bromley by Bow Centre.*

“I found out about the Macmillan Social Prescribing service sometime after I had completed my cancer treatment when I was back at work and a carer for my mum.

# Primary/Community Care and Cancer

# Primary care networks – key to the future

- Primary care networks are small enough to give a sense of **local ownership**, but big enough to have **impact** across a 30-50K population.
- They will comprise groupings of clinicians and wider staff **sharing a vision** for how to improve the care of their population and will serve as **service delivery units** and a **unifying platform** across the country.



# Cancer and Primary Care

- Average practice (8000) has approximately 280 patients living with and beyond cancer
  - this is set to double by 2040
- Over half will have been diagnosed more than 5 years ago
- After a cancer diagnosis people attend more frequently than other patients of the same age
- Many will have unmet needs – physical, emotional, social, financial
- At least 1 in 4 will experience consequences of their cancer or treatment that affect their quality of life



# Personalised Care

- What do you understand by 'personalised care'?
- *Personalised care represents a new relationship between people, professionals and the system. It happens when we make the most of the expertise, capacity and potential of people, families and communities*
- What are essential elements of personalised care?
- *shared decision making, appropriate information provision, personalised care and support planning, supported self-management*
- What different types of support are needed for personalised care?
- *physical, practical, emotional, social, spiritual*

# Personalised Care and cancer

- Treatment summaries
  - Diagnosis & therapy. Treatment intent. General outlook. Potential adverse effects. How to spot recurrence. Advice / rapid re-entry
- Health and well-being events
- Holistic Needs Assessment HNA
  - Physical, psychological, social, spiritual
  - Person-centered care approach
- Cancer Care Review CCR



# Treatment Summary

To support people living with cancer and Primary Care professionals

## Summarises:

- Diagnosis
- Treatments
- Side Effects
- Possible Complications
- Follow Up plans
- Onward referrals

### Appendix 2: Sample Treatment Summary

Dear Dr X

**Re: Add in patient name, address, date of birth and record number**

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.



Diagnosis:	Date of Diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment Aim:
Possible treatment toxicities and / or late effects:		Advise entry onto primary care palliative or supportive care register Yes / No DS 1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for re referrals or queries: In Hours: Out of hours: Other service referrals made: (delete as nec) District Nurse AHP Social Worker Dietician Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Secondary Care Ongoing Management Plan: (tests, appointments etc)		
Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)		
Summary of information given to the patient about their cancer and future progress:		
Additional information including issues relating to lifestyle and support needs:		

Completing Doctor:

Signature:

Date:



# What is a holistic needs assessment, care and support plan

A holistic needs assessment (HNA), is a simple questionnaire that is completed by a person affected by cancer.

It allows them to highlight the most important issues to them at that time, and this can inform the development of a care and support plan with their nurse or key worker.

The questionnaire can be completed on paper, or electronically.

# Sample Holistic needs assessment

## Prostate Cancer Care Plan (please bring this to your next prostate cancer appointment)

We have asked you to complete a Prostate Cancer Care Plan. This provides us with information to give you the best support to manage your condition. This document lists some issues / concerns. Please indicate if any apply to you and if so which you would like to discuss at your next prostate cancer review with your GP/Practice Nurse.

Physical Concerns	Yes	No	Discuss	Practical Concerns	Yes	No	Discuss	Relationship Concerns	Yes	No	Discuss
Problems when urinating or loss of bladder control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Caring for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of Bowel control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Housing or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation or diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Parking or transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	With others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bleeding from the bowel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Work or education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<b>Spiritual /religious Concerns</b>	<b>Yes</b>	<b>No</b>	<b>Discuss</b>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Grocery shopping or making food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loss of faith or other spiritual concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Indigestion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Bone pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Laundry or housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Feeling tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Information needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Poor sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<b>Emotional Concerns</b>							
Problems getting or keeping an erection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
No or loss of sex drive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Sadness or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Unplanned weight gain or feeling swollen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worry, fear or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
Unplanned weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Helplessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

**Please write down anything else you wish to discuss with the GP or Practice Nurse:**

.....

.....

.....

.....

.....

.....

.....

.....

Prostate Holistic Care Plan for \_\_\_\_\_ (Patient's name.)

# Top HNA Concerns from people living with cancer

- **Worry, fear or anxiety**
- **Tiredness/exhaustion or fatigue**
- **Sleep problems/nightmares**
- **Pain**
- **Eating or appetite**
- **Anger or frustration**
- **Getting around (walking)**
- **Memory or concentration**
- **Hot flushes/sweating**
- **Sore or dry mouth**
- **Money or finance**
- **Thinking about the future**

# The Cancer Care Review

- Face-to-face/dedicated appointment/“bring a friend”
- Ask patients to prepare in advance of the conversation
- Use of a template can support the conversation (EMIS, Vision, SystemOne)
- Explore the individual’s understanding
- Discuss holistic needs
- Signposting, self management, referral
- Opportunistic health promotion
- Share CCR output with cancer team(s)?
- Who is best to do this?

# Cancer Care Review IT Templates

## EMIS Web

**Template Runner**

**Cancer care review**

Cancer care review done 15-Jan-2018 05-Dec-2017

Cancer care review next due Follow Up 15-Jan-2018 05-Mar-2018

**Cancer diagnosis discussed**

Cancer diagnosis discussed Text 05-Dec-2017

**Cancer therapy**

Select which cancer therapy patient is on

Discussion about treatment Text

Discussion about complication of treatment with patient Text

**Medication review done**

Medication review done 15-Jan-2018

**Cancer Care plan**

Cancer care plan discussed with patient 15-Jan-2018

**Health & Wellbeing**

Psychological counselling Text

Lifestyle advice regarding diet Text

Smoking status 15-Jan-2018

Smoking cessation advice given Text

Alcohol consumption U/week

Lifestyle advice regarding alcohol Text

Lifestyle advice regarding exercise Text

**Cancer information offered**

Cancer information offered Text

**Social**

Benefits counselling Text

Employment counselling Text

**Carer's details noted**

Carer's details Text comments:

**Information**

[Macmillan Information for Patients](#)  
[Entitlement to medical exemption from prescription charges](#)  
[Macmillan Support home page](#)

## TPP SystemOne

**Macmillan Cancer Care Review Template**

Review Maximising Recovery Care Planning Links and Info

**Review documentation**

Either yourself or the patient may have received a holistic needs assessment or treatment summary to support the cancer care review.

**Diagnosis**

Check patients understanding of diagnosis and prognosis. Any concerns?  
Patients understanding of curative/palliative intent?

Curative treatment

Palliative treatment

**Treatment - Please ensure key treatments are read coded as active major problems.**

Whereabouts in your treatment are you?  
Any concerns with regard to your treatment?  
Any side effects/complications of treatment (including long-term consequences)?

Chemotherapy

Radiotherapy

Hormonal treatment

Discussion about complication of treatment with patient

Medication review done

**Cancer diagnosis discussed**

Date Selection

No previous values

Show recordings from other templates

Show empty recordings

Macmillan - 0808 808 00 00 (Mon - Fri, 9:00 - 20:00) <http://www.macmillan.org.uk>

Information Print Suspend Ok Cancel Show Incomplete Fields

# Robert's story



- High blood pressure & diabetes
- Acute Support Worker talks to Practice Nurse
- Practice Nurse does a multi-morbidity review with Robert
- Robert attends Men in Sheds
- Robert makes contact with the Care Navigator
- Signposted to Macmillan Support Line for financial and legal advice
- After an HNA, linked up to volunteers for practical and emotional support

# When do people need information?



WARNING  
SIGNS



TESTS



DIAGNOSIS



TREATMENT



SURVIVORSHIP



PALLIATIVE  
CARE

# Macmillan Information



# Macmillan's Online Community

- 24/7 peer to peer support network
- Groups dedicated to specific cancer types, treatments, family and friends, even a 'light relief' group called 'Laughter is the best medicine'
- 'Ask an Expert' section allows questions to be put to our range of professionals, including nurses, dietitians, dentists, counsellors majority of whom are volunteers
- Members can also blog about their cancer journeys
- Community champions who are volunteers moderate the site
- **Did you know?**
  - **In 2018, 23,000 new members joined the Community**
  - **Site gets over 100,000 visits a week**
  - **Community is the biggest of it's kind in Europe**

Online  
Community >



Share experiences, ask questions or vent your emotions, with people who understand what you're going through.

# Feedback from the Community

I used the Community when first diagnosed and receiving treatment to ask questions. I don't use it much now as for me...but it is **reassuring** to me that I can turn to it for help when I feel I need it. **I thank you with all my heart.**

**I hope you have some idea of how relieved, less stressed, and happier I am** having read your reply...I note that you posted your reply at 1.30am whilst I was tucked up in bed, probably between hot flushes. To be up and responding at that time of night deserves more than my thanks.

I felt there was always **someone there for me** on my down days after my breast cancer diagnosis.

I had no-one to turn to, and some lovely person answered my question and offered the advice I needed to help my son who was in so much pain. **They were truly my angel that night.**

It made me feel less alone. Even sometimes in the early hours. **It helped me to feel less frightened and less isolated.**

**I felt there was always somewhere there for me** on my down days after my breast cancer diagnosis.

I honestly think **I would have fallen apart without the Online Community.** They helped me keep my sanity. I am on a FB page but they don't have the calming influence of the Champions, or the Experts. I have managed to keep calm and positive for my family and friends BECAUSE of the support I've had on the Online Community. I've not been overly proactive creating posts, but being able to 'talk' to and read about others in the same situation as me has been **as important to my recovery as the actual cancer treatment.** Cancer is a lonely disease...this Community helped me with that.

...every day seems like another journey into the unknown. That is why the Online Community is so important – you hear from real people going through similar issues. **Joining here made me feel less alone in this horrible journey.** It really helps having people to talk to who have been and are going through it with you. I have taken so many positives from here.



[Order information](#) > Resources for health and social care professionals

[A-Z of cancer types](#) >

[Cancer and other health conditions](#) >

[New titles](#) >

[Diagnosing, symptoms, causes, risk factors and tests](#) >

[Organising the practical, work and financial side](#) >

## For health and social care professionals

If you support people affected by cancer in your role we can provide free resources to help.

We have booklets leaflets and other resources for handing out, as well as materials for promoting Macmillan's services. And we have a wide range of resources to help you professionally such as toolkits and information sheets.



Want to make or order something?

[Login](#)

[Create account](#)

[Need help?](#)

<https://be.macmillan.org.uk>

# MACMILLAN CANCER SUPPORT

**We're here to help you find your best way  
through and live life as fully as you can.**

**For information, support or just someone to talk  
to, call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk)**



Talk Cancer training helps you have conversations that could save lives.

**Save the date:**

## **Cancer Research UK: Talk Cancer live online workshop (free)**

**September 24th, 10:30-12:30pm**

Cancer Research UK are hosting a live online workshop to help people feel more confident talking about cancer and health as part of their role. The workshop will give you the knowledge, tools and confidence to have supportive conversations about how people can reduce their risk of cancer, the importance of spotting cancer early and making healthy changes in general. The session is interactive and free to join from any laptop/computer.

**Register to join at [www.cruk.org/talkcanceronline](http://www.cruk.org/talkcanceronline)**



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# Q & A Session