CONSEQUENCES OF CANCER AND ITS TREATMENT

Supporting patients and professionals to identify and self-manage

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Macmillan's new report 'Throwing Light on the Consequences of Cancer and its Treatment' provides estimates, for the first time, on the numbers of people in the UK affected by distressing problems such as chronic fatigue, bowel and urinary problems including incontinence, pain and sexual difficulties. The full report can be found here **macmillan.org.uk/throwinglight**

What are the issues?

- At least 500,000 people in the UK are facing poor health or disability after treatment for cancer – that's 25% of people who have had a cancer diagnosis, but the percentage is much higher for certain cancers and treatments.[1]
- By 2020, almost half (47%) of the population will get cancer at some point in their lives, but the proportion of people who survive will also continue to rise – 38% of these people will not die from it.[2] This means that even more people will be living with the long term effects of cancer and its treatment.
- The long term consequences of cancer and its treatment (CoT) include both physical and psychological effects, such as chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems and lymphoedema.
- Certain cancer treatments also increase the risk of other serious long-term conditions such as heart disease, osteoporosis or a second primary cancer.
- Too many patients aren't given adequate information about the possibility of CoTs. A Macmillan survey showed that 44% of cancer patients were not aware of the possibility of long-term physical side-effects[3].
- Failure to manage CoTs effectively can compromise survival, quality of life for the patient and their carers, recovery and patient experience.
- In addition the economy is impacted, for example through people being unable to return to work or education, or by spending less due to reluctance to leave the house or go on holiday.

What works?

Key principles on CoT for everyone involved in redesigning services and support for people living with cancer, which should be embedded in the re-designed pathway of care[4].

- **Prevent** or minimise CoTs where possible, through healthier lifestyle choices, improved imaging, minimally invasive surgery, targeted radiotherapy and the use of modern drugs.
- **Inform** patients of potential CoTs, with simple strategies for self-management or taking action to seek help.
- **Identify** patients at potential risk, summarising the interventions received in a Treatment Summary that codes potential CoTs so they can be easily recognised in primary care.
- **Assess** potential CoTs through regular Holistic Needs Assessment, the use of 'power' questions and Patient-Reported Outcome Measure (PROM) tools at regular time points.
- **Support** patients through local care pathways for the treatment of CoTs, which include support for self-management and referral to appropriate specialist services.

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[1] Macmillan Cancer Support (2013), *Throwing light on the consequences of cancer and its treatment*

[2] Macmillan Cancer Support (2013), *Cancer mortality trends: 1992–2020.* macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf Accessed June2013

[3] Elliott J, Fallows A, Staetsky L, Smith PWF, Foster CL, Maher EJ and Corner J. (2011) *The health and well-being of cancer survivors in the UK: findings from a population-based survey.* British Journal of Cancer 105, S11–S20

[4] Department of Health (2013), *Living With and Beyond Cancer: Taking Action to Improve Outcomes*

We are focusing on three areas

Improving education and awareness of Consequences of Treatment so that both patients and professionals are empowered:

- Providing information to patients during or at the end of treatment about possible long-term effects helps them to know when to seek help. A summary of the Macmillan resources on the consequences of treatment can be found here **ncsi.org.uk/wp-content/uploads/MAC14343-COT-resources-flyer-FINAL.pdf**

- All primary and secondary care professionals should be aware of potentially embarrassing symptoms, and should ask the patient regularly about on-going problems such as bowel, bladder and sexual issues. A selection of education resources are here **ncsi.org.uk/what-we-are-doing/consequences-of-cancer-treatment-2/cot-resources/** and more are being developed.

Support patients through local care pathways:

- Some CoTs can be helped with simple interventions, while more complex issues will require specialist services.

- Simple interventions include physical activity programmes, provision of information about self-managing problems, public toilet access schemes, pelvic floor exercises, all underpinned by the NCSI Recovery Package. Find more information at **ncsi.org.uk/what-we-are-doing/the-recovery-package/**

- Agreed referral pathways to specialist services are needed for people with chronic and/or complex CoTs, eg:
  - Services for lymphoedema, psychological problems, bowel, bladder or sexual difficulties, pain, speech/swallowing etc.
  - Complex syndromes caused by bone marrow transplant and childhood cancer treatments.

Ensuring Professionals proactively identify patients with problems or future risks:

- The assessment and monitoring of patients for consequences of treatment should begin during the active treatment phase (eg Holistic Needs Assessment and PROMs), and continue for as long as necessary.

- Professionals can use simple questions – such as ‘Do you have any bowel symptoms that are preventing you from living a full life?’ – at any stage to uncover problems, even years/decades after treatment, as some CoTs develop slowly or emerge suddenly years later.

- Future risks can be assessed and monitored (if required) if the GP has a record of cancer treatment from the Treatment Summary.

What can you do next?

- Find out more about how managing CoTs contributes to improved survivorship outcomes, by reading Recovery Package information in the NCSI document *Living With and Beyond Cancer: Taking Action to Improve Outcomes* (DH 2013) at **gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf**

- The following ‘how to guide’ is also useful *Innovation to implementation: Stratified pathways of care for people living with or beyond cancer- A ‘how to guide’* (DH 2013) at **ncsi.org.uk/wp-content/uploads/howtoguide.pdf**

- Ensure EVERY patient at the end of treatment gets the Macmillan booklet *What to do after cancer treatment ends: 10 top tips* which can be found here **macmillan.org.uk/Documents/Cancerinfo/Livingwithandaftercancer/Whattodoaftertreatment.PDF**

- Find out who the CoT specialists in your area are and whether post-treatment referral pathways to these specialists are in place. Support the development of new pathways where they do not currently exist.

- Hold an education event for cancer care professionals, GPs and gastroenterologists to discuss improving care for people with chronic bowel problems after treatment. Contact **Lesley Smith** for more information at **lsmith2@macmillan.org.uk**

- Contact your local Macmillan Development Manager (MDM) for expert advice on developing consequences of treatment services – find their contact details **at macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Healthprofessionalscontacts.aspx**

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