



## MYTH 1 – WE DON'T NEED TO TALK ABOUT CANCER

### WORLD CANCER DECLARATION TARGET 1

Health systems will be strengthened to ensure sustained delivery of effective and comprehensive, people-centred cancer control programmes across the life-course for all, in all countries

### WORLD CANCER DECLARATION TARGET 5

Public stigma towards cancer and cancer patients will improve and damaging myths and misconceptions about the disease will be dispelled

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## WHEN YOU OR SOMEONE YOU KNOW HAS CANCER

### *Talking about Cancer*

For most people, a diagnosis of cancer is a life-changing event. A strong emotional response is experienced by most people - feelings of shock, fear, anger, sadness, loneliness, anxiety are common particularly at the time of diagnosis, during treatment, adjusting to life after treatment and at the transition to palliative care. At least one third of cancer patients experience significant levels of emotional distress<sup>1</sup>, including depression and social isolation (1, 2). Identifying and managing emotional distress is a key component of quality cancer care (3).

Talking about cancer to partners, family members, friends and colleagues can be an important strategy for coping with cancer, and yet many people find talking about cancer difficult. In some cultures and societies today cancer can be discussed in the open and is widely talked about in the media. Yet, this is not the case still in many (if not most) settings, where cancer remains a taboo subject and persons with cancer are subject to stigma and discrimination that may even stop them from admitting they have cancer (4). Negative public perception of cancer can make cancer patients feel invisible, stifle informed public discussion and perpetuate a cycle of fear and misinformation that hinders raising awareness about cancer prevention and the importance of early detection. Countering cultural barriers against speaking about cancer and contesting myths is essential.

Even in settings where community engagement on cancer is high, among individuals, especially men, the level of knowledge of cancer and the willingness to talk about it with friends and family can be low. An example of a campaign seeking to address this issue is the 'Get to know cancer' initiative which aims to help people speak up about their fears about cancer, promote awareness about cancer signs and symptoms and to increase the likelihood of early diagnosis (5). The campaign is using innovative strategies to achieve a broad reach – from pop-up market stalls to partnering with a high profile sports club to reach their global fanbase. Other campaigns specifically challenge the taboos and embarrassment surrounding

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<sup>1</sup> The National Comprehensive Cancer Network (NCCN) describes distress as "an unpleasant emotional experience of a psychological, social and/or spiritual nature that extends on a continuum from normal feelings of vulnerability, sadness and fears to problems that become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crises.



some male cancers (prostate, testicular and colorectal cancers) and create awareness of early signs and symptoms (<http://www.malecancer.org/abouts>).

#### *Cancer Caregiving & Support*

Cancer caregiving can also have an enormous influence on both physical and mental health. Cancer carers – most commonly partners, family members or friends - receive little preparation, information or support to carry out their vital role (6, 7), and as a consequence many carers experience emotional distress and in some cases, depression (8). The importance of carers maintaining social support networks is clear. Family caregivers with more limited social networks are more likely to feel burdened (9); and restrictions in social activities due to caregiving may lead to social isolation. Providing the right type and level of support for both the carer and the person living with cancer can be challenging but ultimately can have wide-ranging benefits for coping and quality of life. Support can come from many sources – partners, friends, family members, health professionals – with some people choosing to join support groups. Support groups can provide a caring and supportive environment for people living with cancer to express their feelings and reduce anxiety and fear (10). Support groups can also provide a place to share information about cancer treatment options and their side effects (11).

#### *Cancer & the Workplace*

There are very real concerns for both people living with cancer and their carers around employment and finances (12). There is a substantial financial burden associated with cancer patients and their carers both in out-of-pocket expenditures and in lost income and benefits (13). Caregiving may also reduce a person's chance of being employed. Many carers are unable to work; need to take leave without pay (e.g. as a result of inadequate carer's leave); have fewer work hours; are in lower paid jobs; or work from home to manage the carer demands (14). In low resource settings, the costs of cancer can be catastrophic for families, with the high costs of cancer medicines and treatments and absence from work, impoverishing families.

For both patients and their carers, receiving support in the workplace can be a significant factor both from a personal and a practical standpoint. A job can restore normality, routine, stability, social contact and income (15). A supportive approach from employers can reduce anxiety and provide the skills and confidence to deal with cancer at work. For employers, making adjustments such as supporting a phased-return to work can be an important factor in getting people back to work successfully (15).

#### *Cancer, body image & sexual wellbeing*

For many, one of the longest lasting, and most devastating consequences of a cancer diagnosis is the impact on sexual wellbeing. Taking breast cancer as an example, where women can experience significant physical changes and long-term effects as a result of surgery, chemotherapy and radiotherapy, sexual intimacy with a partner can be altered for a long period, if not forever (16). Issues of body image and sexuality can have a significant impact on partner relationships and in some cases can be the cause of partner rejection. Both women and men experience these issues. Men living with cancer, particularly prostate and testicular cancer, face issues around self-esteem and sexual intimacy. For prostate cancer survivors, physical changes associated with treatment, including urinary incontinence



and changes to sexual function can have an impact on body image, contributing to anxiety, depression and quality of life (17, 18).

Overall, issues around cancer survivorship - Living with and Beyond Cancer – have not been a global health priority. The facts are that many cancers that were once considered a death sentence can now be treated effectively and many more people are surviving cancer. In the United States alone, there are 12 million Americans living with cancer today. Addressing the concerns and issues that impact the physical health and psychological and emotional wellbeing of cancer survivors and their carers deserves the attention of the global health community.

#### **COMMITMENTS BY MEMBER STATES:**

Presently, there are no specific commitments that address the broader issues associated with cancer survivorship.

#### **GLOBAL ADVOCACY MESSAGE**

The impact of cancer goes far beyond the effect on an individual's physical health with broad consequences on quality of life across the spectrum of emotional, social, sexual and economic wellbeing for both the person living with cancer and their carer.

All cancer patients and their carers should benefit from the best possible measures to promote their psychological, social and emotional well-being, and have access to psychosocial care.

Talking about cancer challenges negative beliefs, attitudes and behaviours that perpetuate myths about cancer, cause fear and stigma and prevent people from seeking early detection and treatment.

Governments, communities, employers and media all have a role to play to challenge perceptions about cancer to create a culture where people are empowered to access quality cancer prevention and care.

#### **THE GLOBAL CANCER CONVERSATION**

Cancer constitutes a major challenge to development undermining social and economic advances throughout the world. Approximately 47% of cancer cases and 55% of cancer deaths occur in less developed regions i.e. countries at a low or medium level of the Human Development Index (HDI). By 2030, medium- and low- level HDI countries will bear the brunt of the estimated 21.4 million new cancer cases per year, with 60-70% of the global cancer burden predicted to occur in developing countries (19).

Yet, while progress is being made towards global commitments for cancer, particularly the adoption by Member States of cancer-related targets and indicators within the *WHO Global Monitoring Framework for NCDs*, there remains limited political will to include cancer control and care measures within a global development framework (20).

Cancer is not just a health matter. It has wide-reaching social, economic and human rights implications, and is a significant barrier to achieving inclusive and equitable development. Inequality is deepening – social and environmental factors and the double disease burden of exposures in many low- and middle- income countries (LMICs) are keeping the bottom billion locked in chronic poverty and threatening national economies. The staggering risk that cancer



poses to economic growth and development is still not recognised despite the fact that we know that this risk can be managed effectively and that a return on investment in health is possible. The cost of cancer is estimated to reach \$458 billion in 2030 (21) yet the World Health Organization estimates that a basic package of cost effective strategies to address the common cancer risk factors (tobacco use, alcohol abuse, unhealthy diet and physical inactivity) would cost only USD 2 billion a year (22).

Less than 3% (USD 503 million out of USD 22 billion) of overall development assistance for health (DAH) was allocated to NCDs in 2007 (23), and only 5% of global spending on cancer is in the developing world. This is despite the vast majority of preventable premature deaths from these diseases occurring in developing countries.

There is an urgent need to mobilise the cancer community to make governments accountable for existing commitments and to advocate for mainstreaming cancer in the post-2015 development agenda. Broadening the future internationally-agreed development goals to include proven economically-sound interventions that span the entire cancer control and care continuum can strengthen health systems and increase capacity to respond to all of the challenges to sustainable development.

#### **COMMITMENTS BY MEMBER STATES:**

For the first time, all Member States of the United Nations have agreed that non-communicable diseases (NCDs) constitute a major challenge to socioeconomic development, environmental sustainability and poverty alleviation. The UN Political Declaration in 2011 committed governments to strengthen and integrate NCD policies and programmes into health planning processes and national development agendas. Further to this Declaration, in June 2012, the Rio+20 declaration on Sustainable Development acknowledged that the global burden of NCDs constitutes one of today's major challenges for development (24); and in 2013, the World Health Organization (WHO) adopted the Global Action Plan for the Prevention and Control of Non-communicable Diseases 2013-2020, declaring that the **prevention of NCDs including cancer is a precondition for, an outcome of and an indicator of all three dimensions of sustainable development: economic development, environmental sustainability and social inclusion.**

#### **GLOBAL ADVOCACY MESSAGE:**

Investing in prevention and early detection of cancer is cheaper than dealing with the consequences.

As the conversation on the 2015 development agenda gains momentum, it is an imperative that cancer and other NCDs are mainstreamed within development cooperation initiatives, internationally-agreed development goals, economic development policies, sustainable development frameworks and poverty-reduction strategies.

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