# FINANCIAL TOXICITY IN CANCER CARE



Financial toxicity is a wide-ranging term often used interchangeably and without distinction from financial burden or distress, or economic or financial hardship.(1) Financial toxicity is a significant issue among people with cancer but not well understood by all. The emerging concept of financial toxicity describes the impact of changed financial circumstances due to cancer and cancer care. Financial toxicity is attributed to increased expenses paid by individuals and families, ongoing out-of-pocket costs and payment for unsubsidised services or medicines, and reduced income. Financial toxicity impacts physical, psychological, social, and financial health and is increasingly compared to the toxicities of cancer treatment such as fatigue, pain and nausea. While a number of definitions exist in the international literature, it is important that the term financial toxicity is clearly defined and commonly understood by Australian health professionals and policy makers.

## Definition of financial toxicity and its impacts

COSA endorses the following definition of financial toxicity:

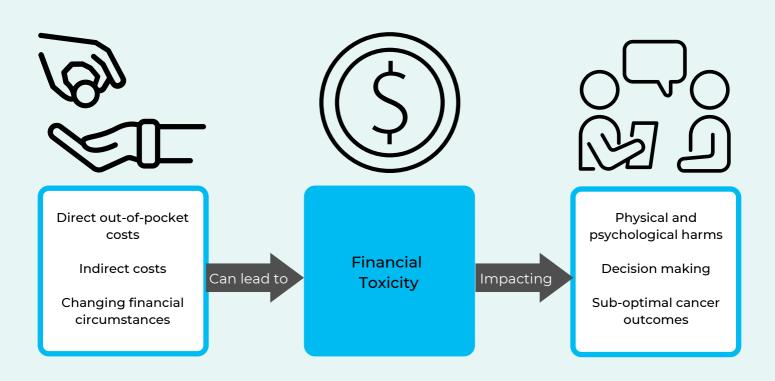
"The negative patient-level impact of the cost of cancer. It is the combined impact of direct out-of-pocket costs and indirect costs and the changing financial circumstances of an individual and their household due to cancer, its diagnosis, treatment, survivorship and palliation, causing both physical and psychological harms, affecting decisions which can lead to suboptimal cancer outcomes."

## Financial toxicity in cancer treatment and care

Financial vulnerability, and its impact on an individual's life, their decisions and mental health, has been the silent experience of many people affected by cancer and has, until recently, often been left unaddressed. A cancer diagnosis changes people's lives, and the financial effects can be immediate or realised long after treatment has finished, through palliation and beyond for the family. Diminishing an estate by using superannuation or insurance funds, either to fund living expenses when income is reduced, or to access 'last resort' treatment options, can leave surviving family members in debt or in poverty.

Financial toxicity includes two inter-related elements; objective financial burden and subjective financial distress. (2,3,4) Objective financial burden is the measurable out-of-pocket costs related to cancer treatment and its effects, and the nonmedical costs associated with seeking treatment or improving wellbeing. Subjective financial distress is the experiences of individuals and their families, including distress due to erosion of household wealth, loss or reductions in essential and dispensable income, and costs of support and resources needed post-cancer treatment. As financial toxicity becomes increasingly recognised as a chronic outcome of cancer, the financial impact of cancer is increasingly compared to other physical side effects, such as fatigue, pain and nausea, or the psychological toxicities of cancer treatment. (2) We therefore argue for preventing, minimising, and managing financial concerns, from diagnosis to survivorship or bereavement, as we do other toxicities. Financial toxicity should not be an acceptable consequence of cancer care in Australia, where healthcare is expected to be effective, accessible, and equitable.

Financial toxicity is not solely influenced or predicted by the total out-of-pocket costs paid. Rather it is a function of expenditure and pre-cancer wealth. For some patients, \$20 for parking per treatment visit can be the reason they avoid care, for others, thousands of dollars from their savings or superannuation may be used to go overseas for treatment. The fear of financial implications of cancer care can influence healthcare decisions. Non-adherence to recommended treatment, and trade-offs between essential living expenses, such as food, and treatment costs could lead to poorer health outcomes. Alternatively, the desire to be well or survive can result in making significant financial decisions such as the early withdrawal of superannuation or selling a house to pay for care. While changed financial circumstances increases financial toxicity within the first six months of diagnosis, cancer treatment and care can continue for many months or years(6). The impact of financial toxicity is therefore not always immediate, and decisions made at diagnosis can have ongoing implications for physical, psychosocial and financial health and impact the wider family.(5,6)



# Why an agreed definition on financial toxicity is important

Defining financial toxicity is important for awareness, measurement and reporting presence and impact, and to identify solutions that reduce the financial impact of cancer care on patients. A concerted effort by both the health professional community and patients is required to begin to prevent, minimise and manage financial toxicity. Each component of the health system has a responsibility to address financial toxicity - from specialists who set their own fees, to State and Territory health services providing care, and the Commonwealth who set legislation to deliver healthcare and social services.



The Commonwealth's endorsement of Recommendation 3 of the MBS Taskforce Review to 'Develop and mandate a consistent documented procedure with appropriate provision of information to assist providers in explaining costs to consumers prior to a course of treatment' is an opportunity for action to improve understanding costs and their implications by health and medical professionals, and health services to ensure patients can make fully informed decisions about their cancer care.7

Opportunities to reduce out-of-pocket costs must feature within the proposed National Medicines Policy review, and local initiatives to identify people vulnerable to financial toxicity early such as through the use of risk screening tools and ensuring informed financial consent, could connect people with financial counselling services.

The Australian cancer community is ready to advance its efforts beyond discussions that only focus on defining financial toxicity. This COSA definition statement provides a baseline understanding of financial toxicity and the scope for future work. Further action must focus on engagement and communication with cancer clinicians, consumers and the wider community, and support collaborative action in finding solutions.

#### References

- 1. Witte J, Mehlis K, Surmann B, et. al. Methods for measuring financial toxicity after cancer diagnosis and treatment: a systematic review and its implications. Ann Oncol 2019; 30: 1061-1070
- 2.Gordon LG, Merllini KMD, Lowe A, Chan RJ. Financial toxicity what is it and how to measure it. Cancer Forum 2017; 41: 30-35
- 3. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin 2018; 68: 153-165
- 4.Zafar YS, Abernethy AP. Financial Toxicity, Part 1: A new name for a growing problem. Oncology 2013; 27: 80-149
- 5.Gordon LG, Beesley VL, Mihala G, et. al. Reduced employment and financial hardship among middle-aged individuals with colorectal cancer. Eur J Cancer Care 2017; 26
- 6.Chan R, Cooper B, Paul S, et. al. Distinct financial distress profiles in patients with breast cancer prior to and for 12 months following surgery. BMJ Supportive & Palliative Care 2020.
- 7. Department of Health. An MBS for the 21st Century Recommendations, Learnings and Ideas for the Future. Canberra: DoH, 2020.

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