

What really happens when someone is diagnosed with cancer? The case for personalized care

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A diagnosis of cancer impacts every aspect of a person's life, far beyond the physical issues related to the disease and treatment. Needs include finances, information, emotional and practical support, and personal care. As treatments are designed with great precision, care needs to be given with greater personalization.

Success in treating cancer should not only be measured by survival statistics but by attempts to understand quality of survival.

This article discusses the times and types of need for personalized care, the domains of living with and beyond cancer, and presents some of the systemic approaches required to meet holistic need.

A life is changed by a diagnosis of cancer. The moment of a cancer diagnosis is seismic for the person affected. At that point the person becomes a citizen of what Susan Sontag described as the "Kingdom of the Sick" (1). The transition of this unwanted citizenship is undoubtedly a trauma. The US-based oncologist and pancreatic cancer survivor, Mark Lewis has written of the "tinnitus of terror" he experienced at his own diagnosis when he was unable to hear or absorb the information he was being given. He has seen the same effect in his own patients when "cancer" is mentioned in a diagnostic consultation (2). The effect is such that information processing and fact retention are markedly affected. There is significant literature showing how clinical teams should and could improve the process of breaking the bad news of a cancer diagnosis (3). Much is forgotten and important questions can go unasked. Recording the consultation is one first step in allowing the person affected to have full recall of the consultation and to share with their own networks. Studies prove the utility of recorded consultations, and now the availability of mobile phones mean that recording technology will often be at hand (4).

A cancer diagnosis creates multiple information needs ranging from details of the diagnosis through to treatment options and the likely impact of therapy. Desire for information is high amongst people affected by cancer and this is frequently unsatisfied by their healthcare providers. People request information about all possible treatments and side effects, with only 6% not wanting this information (5). It is neither possible nor appropriate to attempt to generalize groups who may not need detailed information. Neither age, gender nor

education level has been able to distinguish a group that could safely be provided with less detail (6).

Servicing information needs appropriately is challenging as patients will have different preferences for information materials (text, video etc) and different educational levels.

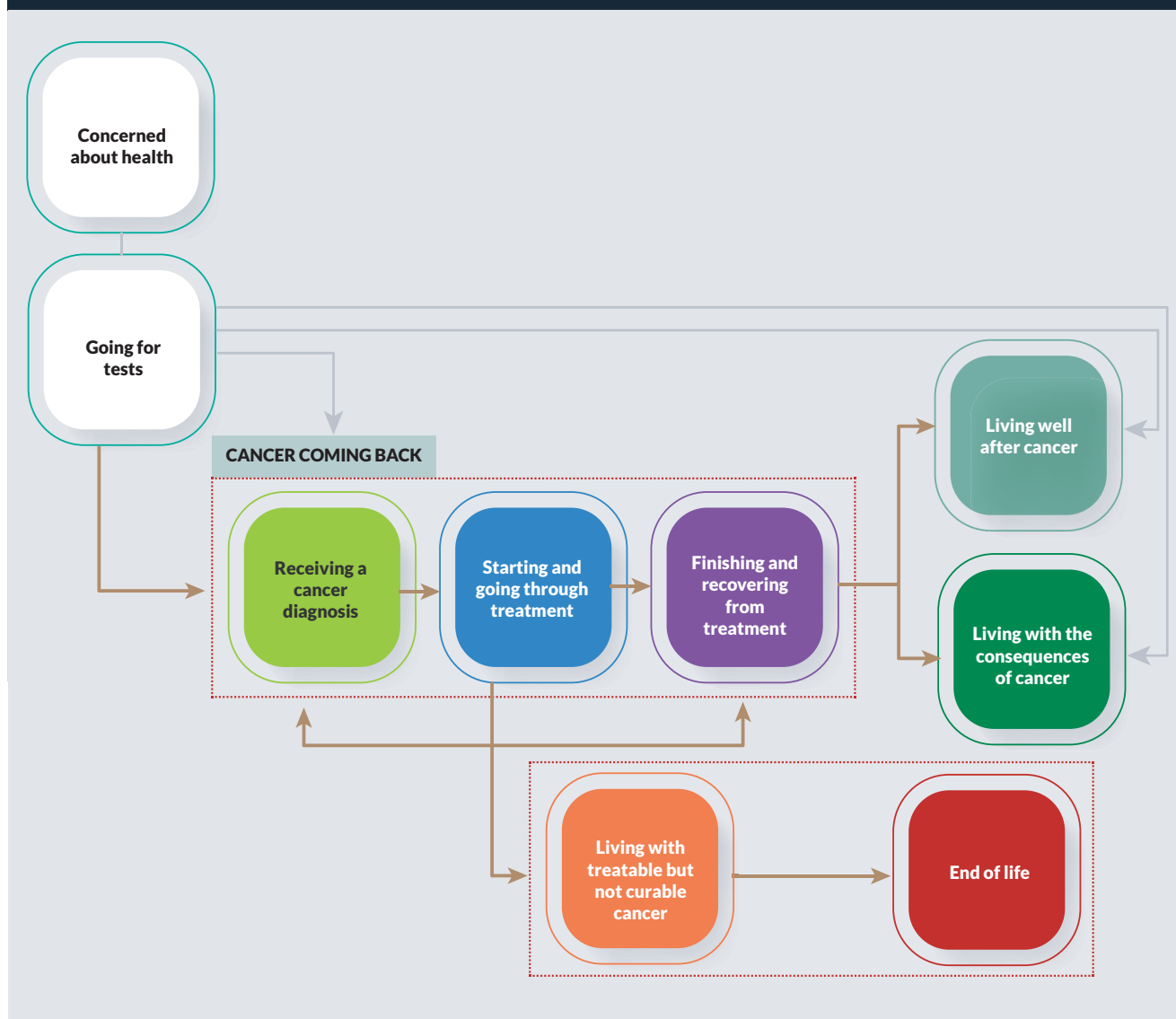
Personalized care in cancer

After the cancer diagnosis, a clinical team can begin to formulate and agree a treatment plan, and the person affected by cancer begins that therapeutic process. This moment is also the beginning of effects which will extend far beyond in both time and implication. Like a stone dropped in a pond, the diagnosis forms ripples which extend further onwards and outwards as all domains of life become affected; work, finances, relationships with family and friends are all potentially impacted. Treatments can cause short term side effects and late consequences which can impact any organ system. Fear of recurrence and worry can create existential distress and psychological morbidity. This is the territory commonly referred to as survivorship.

The US National Coalition of Cancer Survivorship defines survivorship as "the experience of living with, through and beyond a diagnosis of cancer" (7). This concept of "living with and beyond" cancer is perhaps a preferable term to "survivorship". "Survivor" has unhelpful linguistic ties to "battles" and "fights" and some of the other militaristic terms that have rightly become controversial (8).

Another important term to define is "personalized care". Much of the modern dialogue around cancer therapy focuses on the issue of "precision therapy". Precision therapy refers to medical care delivered based on genomic or molecular

Figure 1: Times of need: diagram showing the times of need Macmillan has identified within the cancer journey. Target times of need are shown within the red dotted line



profiling. The FDA in the United States defines it as “an innovative approach to tailoring disease prevention and treatment that takes into account differences in people’s genes, environments, and lifestyles.” The term “personalized medicine” is often used to mean the same thing and the US National Cancer Institute uses interchangeable definitions for personalized and precision medicine (9). The US National Research Council prefers the term precision, but only due to concerns that “personalized” may be misinterpreted to mean that theories are developed specifically for an individual (10). The most important distinction here is between “treatment” and “care”.

Personalized care is designed to meet the needs of an individual patient. This distinction is often captured by the adage; precision medicine is about tackling what is the matter with the patient whilst personalized care focuses on what matters to the patient. Macmillan understands personalized

care as being “designed in collaboration with the person who needs it, or with someone who knows them well, so that it is tailored to meet individual needs” (11).

Personalized care should be a foundation stone for all the care we deliver in cancer regardless of disease type, geography, or resource. Personalized care is agnostic of molecular mutations or therapeutic genomic targets. Treatments may vary enormously according to the cancer, local economy, and healthcare structure but the principles of care should be a universal truth centred on compassion, respect and putting the patient first.

In the United Kingdom, we have estimated that there are approximately 3 million people living with cancer and that 66% of them are aged over 65. By 2030 we estimate the number will be as high as four million, partly explained by average survival times which now exceed a decade (12). Incidence rises as a consequence of ageing populations and better treatments

Time of need	Information needs
At diagnosis	<p>Guidance on what to read is provided in a “read later” format as ability to process information is limited.</p> <p>Information pack signposting resources e.g., online nurses, welfare officer.</p> <p>Create opportunities to clearly signpost this.</p>
During Treatment	<p>Active check-in, support and guidance is necessary to begin processing and planning for financial impact.</p> <p>In-person check from nurse, welfare officer, volunteer.</p> <p>Clinical setting is key location for reaching people living with cancer however their time and energy may be low.</p> <p>Ideally one-to-one advice is desired – a consistent point of contact throughout providing continuity.</p>
Finishing and recovering from treatment	<p>Option for follow up support available by phone consultation or pre-booked appointment.</p> <p>Clear direction to online resources to help implement strategies and access resources.</p> <p>Returning to the new normal may require specific support e.g., rights returning to work, changes to benefits, provide guidance through online resources and a helpline.</p>
Living well after cancer	<p>Potential to engage people living with cancer as a peer advocate to support those newly diagnosed in understanding what to expect.</p>

leading to higher prevalence. These citizens deserve holistic care of their multiple needs.

Healthcare systems will set key performance indicators for success usually built around metrics related to numbers of cancer diagnoses, stage at diagnosis and survival estimates. These are appropriate benchmarks for a governance system but counting people affected by cancer tells us nothing about the quality of their survival and whether lives are lived in distress or comfort. Survivorship metrics are difficult to agree and harder to collect but are possible. In England the commitment to use the EORTC QLQ-C30 to measure quality of life in people diagnosed with cancer is an example of attempts to collect meaningful data at scale on the experience of living with cancer (13). The efforts to record these metrics should be respected and wherever possible improved, as to paraphrase the management consultant Peter Drucker: “What gets measured gets managed”.

Times and types of need

Beyond the diagnosis, a person affected with cancer can expect to transition through different states of treatment and disease where needs will change accordingly. We can characterise these as “times of need” (Figure 1) and understand that people will follow different routes through

these times of need and be in those states for varying lengths of time. We recognize that the term “palliative” is too often interpreted to mean care at end of life however the welcome advances in therapeutics mean that now in very many cases people may have incurable disease in which palliative treatment can extend life by many years. In this circumstance, the term “treatable but not curable” is preferred. For people with treatable but not curable disease there are new existential problems related to uncertainty of prognosis which impacts on important decisions, for example those related to work and finance.

It is recognized that the methods we choose to meet needs will change over time (see the example of cancer information in Table 1).

Addressing the information needs will also change over time as patients become familiar with treatment jargon and more expert in their own condition. Service providers should work with people affected by cancer to provide information resources that are accessible at all stages of a cancer experience.

Holistic needs assessment

To understand the multiple and varied needs of people affected by cancer, there needs to be a mechanism for

Table 2: Types of need

Time of need	Examples
Physical	Fatigue, nausea, sleep and eating issues and bowel problems can all affect people's ability to attend places of work or education.
Emotional and psychological	Sadness, anxiety, fear of cancer recurrence, depression. Cancer treatment related cognitive impairment. Loss of libido.
Financial (including work and education)	Unable to work or attend education due to fatigue, treatment burden or physical incapacity. Impact of loss of earnings on wider family group. Lack of clarity on state support and benefit. Financial toxicity of treatment from direct costs and indirect (travel to care, time off work).
Practical and personal care	Feeling so ill that they cannot complete everyday tasks, being too fatigued to leave bed etc. Needing support for activities of daily living.
Information	Details of treatment and side effects. Signposting for practical support. Details of alternative treatment options.
Spiritual and religious	Thoughts about death and dying, searching for a greater meaning in life after a cancer diagnosis, feelings about faith and religion.

systematic enquiry for the problems and concerns that the person is facing. In England this is recommended to be achieved by Holistic Needs Assessment (HNA).

In 2015, a Cancer Strategy for England was published and recommended an assessment of holistic needs, now accepted as best practice (14). Through promotion, investment and training there is now a significant experience in using HNA for the benefit of people affected by cancer (15). The HNA concept is well established across the United Kingdom but other forms of distress screening have been used in other geographies.

Distress screening/HNA can reveal multiple problems. A previous Institute of Medicine report identified four domains of survivorship care that are needed to comprehensively address medical needs after primary treatment; specifically prevention, surveillance, intervention, and coordination (16). Within these domains at Macmillan we would recognize six distinct types of need (Table 2).

These needs require distinct and specialist approaches which will usually entail sourcing expertise, for example, related to financial support. Despite the high prevalence

of these problems, they are rarely properly valued and recognized with National Cancer Plans (17).

Key workers

In many clinical environments, the increasingly specialization of cancer care creates silos of expertise where the area of concern is narrow, but knowledge is deep. Expert care with high levels of specialization may drive improved outcomes for cancer control but may do so at the expense of holistic care. If an individual's cancer is being managed by many dedicated therapeutic experts, who is to assume the role of oversight and ensure that holistic assessment is conducted and acted upon? Consider the person with advanced breast cancer receiving pain relief advice from the palliative care team, regular medications from their primary care provider, systemic anti-cancer therapy from their local cancer centre, and stereotactic radiosurgery from a tertiary provider. In this complex network of healthcare professionals, we have recognized the value of a "key worker" concept. A healthcare professional tasked with ensuring holistic needs are assessed and met. In England this is most often a Cancer Nurse Specialist who would formulate a

care plan based on HNA outputs (15). In other health economies this is often referred to as a Survivorship Care Plan. The key worker needs to have a good understanding of the local health economy so that a person affected by cancer can be signposted to appropriate care, which may often sit outside of healthcare and within the wider community. In some systems this role can be adopted by a care navigator with expert knowledge of local services which they can match to patient need.

Delivery

In order to deliver personalized care, systems need to provide the tools and spaces for holistic needs assessments and support the workforce to provide it. Workforce support requires both time and training.

Delivering comprehensive services that meet the holistic needs of cancer patients is likely to be beyond the capacity and ambition of most funded health services. Needs are complex, varied and will vary in different geographies. In that context it is often local communities themselves that are best suited to support holistic need. Cancer services are encouraged to stocktake available civic services, voluntary groups and charities within their communities that can be signposted as a result of HNA. Data sharing agreements may be necessary to

allow flow of relevant details for patient care.

Conclusion

A personal reaction to a cancer diagnosis is likely to be as individual as a genomic signature. Cancer impacts people differently and that is why we want people to be treated as individuals. All of us have different motivations, experiences, fears, hopes and desires and to quote Walt Whitman from his 1855 poem “Song of Myself”, we all “contain multitudes”.

Access to personalized care means people have choice and control over the way their care is planned and delivered. It is based on what matters to them and their individual strengths and needs. Making care personalized aims to support people with cancer to make decisions about their care through identification of their concerns and goal setting facilitated by health and social care professionals.

To respect this, cancer services need systems that prioritize assessment of holistic need. These needs can be addressed in a care plan which may be best delivered in collaboration with community groups outside of cancer treatment.

Surviving cancer well depends on good quality personalized care. Personalized care should be valued as a fundamental of good cancer care and seen as a basic right, not a luxury item. ■

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