




Hospital and Community-based Psychosocial Care for Patients with Cancer and their Families:

A Model of Care for Psycho-Oncology

September 2020





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Foreword

The National Cancer Control Programme is delighted to publish the Hospital and Community-based Psychosocial Care for Patients with Cancer and their Families: A Model of Care for Psycho-Oncology. Building on the National Cancer Strategy 2017-2026, it sets out in detail how psychosocial support for cancer patients and their families will be developed in Ireland. This Model of Care will guide the development of Psycho-Oncology over the next number of years.

Psychological distress caused by a cancer diagnosis is recognised as a major influence on quality of life and wellbeing for patients and their families. This Model of Care offers a roadmap for navigating this challenging life event. It recognises the necessity for a comprehensive psychosocial support service that spans the acute hospital, satellite treatment centres, primary care and the community and voluntary sectors, who all have a vital role to play in promoting and enhancing psychological wellbeing and in supporting patients and their families.

It is very timely, given the publication of the National Cancer Strategy 2017-2026 with an added emphasis on Psycho-Oncology services at both Cancer Centre and community level. It is particularly important that a comprehensive patient pathway is identified in this Model of Care as this is one of the recurring themes that cancer patients highlight as an area of concern. It is hoped that this model will provide an accessible, flexible and appropriately skilled response whether their level of psychosocial distress is mild, moderate or severe.

Yours sincerely

Dr. Risteard O Laoide

National Director
National Cancer Control Programme

Acknowledgements

The development of a Model of Care for Psycho-Oncology in Ireland is an important addition to the provision of psychosocial support now and in the future.

I would like to extend a sincere thank you to the following individuals and organisations for their collaboration and support: the Working Group for the Model of Care; the Psycho-Oncology Advisory group of the NCCP; patient representatives; Cancer Centre staff; Ms Dorothy Thomas, Community Support Network Co-ordinator, Irish Cancer Society; Ms Rachel Morrogh, Director of Advocacy and External Affairs, Irish Cancer Society; NCCP staff and Cancer Support Centre representatives. I would also like to extend a sincere thanks to Ms Deirdre Love, Project Manager for the Cancer Survivorship and Psycho-Oncology Programmes, NCCP.

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Abbreviations

CNS	Clinical Nurse Specialist
CPD	Continuous Professional Development
DoH	Department of Health
GP	General Practitioner
HSA	Health and Safety Authority
HCP	Healthcare Professional
HSE	Health Service Executive
MDT	Multidisciplinary Team
MDM	Multidisciplinary Meeting
NCCN	National Comprehensive Cancer Network
NCCP	National Cancer Control Programme
SACT	Systemic Anti-Cancer Therapy

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Introduction

This Model of Care for Psycho-Oncology was developed by the National Cancer Control Programme in order to provide a framework to support the way psychosocial care is delivered to patients with cancer and their families. The document aims to promote psychological wellbeing and improve access to psychological services at both acute hospital and community level.

Improvements in collaborative practice between designated cancer centres, Systemic Anti-Cancer Therapy (SACT) hospitals and primary/community care settings across the country, will be facilitated through the implementation of this Model of Care.

This Model of Care draws upon the recommendations of the current National Cancer Strategy 2017-2026 and the recent NCCP National Cancer Survivorship Needs Assessment.

By delineating a pathway for the development of services nationally, it will be an essential tool to help ensure that people get the right care, at the right time, by the right team and in the right place. The Model of Care defines what a comprehensive Psycho-Oncology service should look like and offers actionable steps to help services provide such care.

The Model of Care was developed by a multidisciplinary working group comprising of healthcare professionals from acute and community settings across the country, as well as management, and patient and family advocates (Appendix 4).

The group recognises that children and teenagers with cancer and their families have specific needs. And therefore a separate Paediatric Psycho-Oncology Model of Care is currently being developed, based on the National Cancer Strategy and International Standards of Care for Paediatric Psycho-Oncology.



Rationale for developing the Model of Care

This document describes the Model of Care for Psycho-Oncology services envisioned in Ireland, based on international best practice. It is proposed that the Model of Care will be delivered via a collaborative/integrated care approach. It covers the full spectrum of care provided in cancer centres, SACT hospitals and in the community. This approach was developed with the joint involvement of primary, secondary and tertiary sectors.

Recognising and treating distress in patients with cancer is an important health priority. While distress levels can be high, awareness of and access to supports can be a substantial issue. A study conducted by Forsythe et al. (2013), indicated that only 40.2% of survivors reported having had a discussion with their clinicians about how cancer may have affected their emotions or relationships. In addition, more than 90% of the barriers identified to the utilisation of professional counselling or support groups by survivors involved a lack of knowledge about, or perceived unavailability of, services.

A recent Cochrane Review has highlighted the need for distress screening to be seen in the context of available services to meet needs (Schouten et al., 2019). The main rationale for developing this Model of Care is that for those who screen positive for distress, a comprehensive evaluation of their needs and referral to the appropriate type, setting, and level of service will need to be developed and provided as part of the clinical pathway (Pirl et al., 2014; Smith et al., 2018).

In addition to the distress that patients with cancer can experience as noted above, research highlighting the psychological impact of a cancer diagnosis on family members has indicated that family members can display even higher levels of depression and anxiety than cancer patients themselves (Cho et al., 2018; Sklenarova et al., 2015). Cancer often changes roles and responsibilities within the family. Emotional and physical needs may also change. Feelings of not being able to take the burden from the patient may cause distress, as well as feelings of helplessness, guilt, and fear about the future.

Cancer often changes roles and responsibilities within the family. Emotional and physical needs may also change.

Aims and Objectives

Aim

To develop a Model of Care for patients with cancer and their families in order to promote psychological wellbeing and to improve access to psychological services. The Model of Care will facilitate the improvement of collaborative practice between the designated cancer centres, SACT hospitals and primary/community care settings across the country.



Objectives

To support patients and their families to maintain optimum levels of psychological wellbeing as they transition through the various stages of their cancer journey, with a focus on resilience building from the outset.

To guide the planning and building of capacity in Psycho-Oncology MDT teams and community cancer support within the existing system.

To increase awareness of the supports that are available to patients and families and how to access services when needed.

To enable patients to access a range of support services and allow appropriate interventions to be delivered closer to home either face-to-face or remotely using online platforms, which will result in a more efficient service overall.

Background

The field of Psycho-Oncology is a relatively new discipline with a rapidly expanding evidence base. Over the past few decades, several lines of research have established that psychosocial problems, such as anxiety, depression, post-traumatic stress, fatigue, and cognitive complaints, are common and consequential in patients with cancer. The word “distress” was chosen deliberately to capture a broad range of adjustment difficulties commonly associated with cancer and is the preferred term to describe the psychological challenges that people affected by cancer experience.

Cancer-related distress is best conceptualised as existing on a continuum of severity, ranging from mild (adaptive, ‘normal’ levels of sadness and fear) to severe (disabling symptoms such as clinical depression, anxiety, panic disorder, body image problems or relationship and family breakdown). It has been reported that between 20-52% of patients show a significant level of psychosocial distress (NCCN, 2019). Estimates of the prevalence of distress vary due to the type and stage of cancer, patient demographics (age, gender, and race), economic factors and levels of social support (Wen et al., 2019).

As reported in the NCCP National Cancer Survivorship Needs Assessment 2019, while the majority of cancer survivors manage to live well after a cancer diagnosis, it is estimated that 25% of cancer survivors have at least one physical or psychological consequence as a result of their treatment that affects their life in the long-term and indeed many more have a shorter-term symptom burden that needs addressing (Mullen & Hanan, 2019).

The psychological care of patients experiencing cancer is considered an integral part of quality cancer care (Holland & Alici, 2010), with up to half of cancer patients reporting distress and up to a third will warrant referral to a Psycho-Oncology service (Carlson & Bultz, 2003).

International guidelines indicate that routine assessment of psychological distress among patients with cancer is a minimum standard of practice in oncology care and that a multidisciplinary Psycho-Oncology service should involve psychology, psychiatry, nursing and social work.

Early evaluation and screening for psychological distress leads to timely and effective management of psychological sequelae, which in addition aids medical management and resource allocation in hospital settings (Carlson & Bultz, 2003; Holland & Alici, 2010). Failure to recognise and treat distress leads to problems such as difficulty in making decisions about, and adhering to treatment, additional visits to the GP, and greater demand on time resources and increased stress for the oncology team (NCCN, 2019).

In a recent study (Smith et al., 2019), patients reported getting advice about emotional distress approximately half the time (54%), possibly reflecting clinicians’ lack of familiarity and resources for dealing with distress and patients’ reticence to mention mental health issues as a result of social stigma.

The experience of cancer and its longer term physical and psychological consequences can also have a significant economic cost:

- Healthcare costs for people with long-term conditions are 50% higher in people with depression and/or anxiety disorders.
- Psychological therapy reduces physical healthcare costs by an average of 20% (meta-analysis of 91 studies). When data is available on the cost of psychological treatment and physical healthcare, savings exceed costs (Layard & Clarke, 2014).

Guiding principles for the Model of Care (National Cancer Strategy 2017-2026)

One of the recommendations of the current National Cancer Strategy is the requirement to establish Psycho-Oncology MDTs in each of the designated cancer centres. Two essential issues need to be considered when planning Psycho-Oncology and psychosocial support services:

- The appropriate level of expertise and intervention required relative to patients' needs; and
- The development of a model for Psycho-Oncology that has the capacity to cross the acute primary and voluntary services (DoH, 2017).

It is crucial to ensure that the psychosocial support needs of patients are communicated to and integrated into care provided by their treating oncology teams. It is recommended that a representative from the Psycho-Oncology MDT (e.g. CNS) attend the weekly general Oncology and Haematology MDMs where appropriate.

Shared decision making with patients with cancer and their families should be encouraged. It is also envisioned that patients with cancer will be active partners when accessing psychosocial services.

The recently published national mental health policy report, *Sharing the Vision* (DoH, 2020) promotes early access to psychological support in various settings. The policy promotes the provision of individualised care to those who need help as soon as possible. The Psycho-Oncology Model of Care reflects these aims.



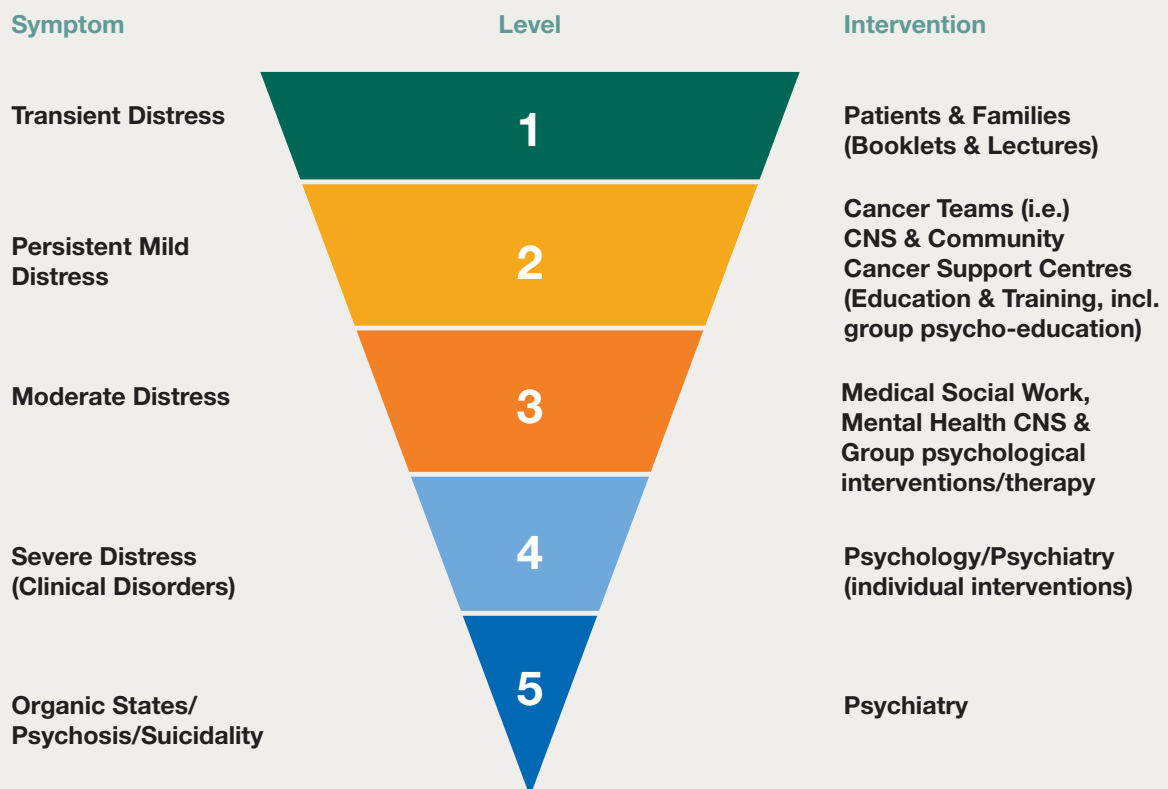
Distress, while a very real aspect of the cancer experience, has been increasingly acknowledged in Ireland as needing professional support and intervention from a variety of professionals. Patients may require psychological care in different contexts as the severity of their distress differs and as they progress through their illness. Care is delivered by different members of a Psycho-Oncology MDT with the expertise to address the needs of patients with cancer and their families depending on the stage and stability of the patient's disease.

The current National Cancer Strategy incorporates a Model of Hospital-Community Psycho-Oncology & Psychosocial Care (figure 1), recognising the spectrum of needs of patients and the services that are available in both the acute and community settings, through a hub and spoke model of delivery (DoH, 2017).

It also recognises that the establishment of Psycho-Oncology MDTs in each of the cancer centres is required to provide a comprehensive hospital-based and/or outpatient clinical service. The services will also link in where possible with a community support function provided by Community Cancer Support Centres and groups.

This model also facilitates the provision of Psycho-Oncology support to centres where patients are being treated in a ‘hub and spoke’ model. It is recommended that Oncology, Haematology and Psycho-Oncology MDTs facilitate communication and information about the psychosocial supports that are available for patients, in cancer centres, Systemic Anti-Cancer Therapy (SACT) hospitals and Community Cancer Support Centres.

Figure 1. **Proposed Model of Hospital-Community Psycho-Oncology & Psychosocial Care – National Cancer Strategy 2017-2026***



**(modified from O'Dwyer & Collier, St. James's Hospital, 2003)*

Level 1

Level 1 care is provided to patients, families and carers, supported by public lectures, information leaflets and booklets, peer support programmes and online resources produced by the cancer centres and the voluntary/charity sector. A variety of services suitable for transient distress are available at Community Cancer Support Centres.

Level 2

Level 2 care is for those with more significant morbidity who can be managed in cancer centres by cancer clinical nurse specialists or in primary care by staff such as GPs, community mental health nurses and health promotion officers. Services should provide care to both patients and their families. The staff involved in providing the support should receive appropriate training from Psycho-Oncology services based in the cancer centres. In some cases cancer support services in the community will provide interventions and programmes at this level, bridging between hospital services and community care.

Level 3

Level 3 care is for patients with moderate degrees of distress and should be managed by trained mental health practitioners in hospitals and in the community (including community cancer support centres, where such expertise exists). This includes clinical/counselling psychologists, psychotherapists, mental health clinical nurse specialists and social workers, working within the scope of their practice/expertise.

Level 4 and 5

Level 4 and 5 care is for patients with severe and pervasive distress and requires more intensive input from senior specialist mental health professionals, (e.g.) consultant psychiatrists or clinical/counselling psychologists, at more advanced career grade level, ideally principal. It will be necessary for patients at this end of the continuum to attend Psycho-Oncology services in a cancer centre where specific expertise in interventions for cancer-related morbidity, including steroid-induced psychosis, severe cancer-related fatigue or body image disorder, will be available in a manner similar to services for physical treatments in cancer.

The varying degrees of psychosocial distress make it essential that patients are able to access different types of support. The degree of severity experienced by the patient will dictate the level of intervention and expertise required. The model presented above is based on this understanding and has a range of specific psychological interventions, matching each level of intervention with the level of distress or morbidity experienced by the patient with cancer. As a layered care approach to service provision, this model is flexible to meet the needs of all patients and their family members with the intervention selected according to the type and severity of psychological morbidity. As such, it ensures the most efficient use of resources, while also ensuring that interventions received are appropriate to the level of distress.

The Psycho-Oncology MDT provides care across the spectrum of all levels of distress and the current Model of Care will be implemented by building up the multi-disciplinary Psycho-Oncology teams in each designated cancer centre (Appendix 1). It is envisaged that as part of the National Cancer Strategy the establishment of Psycho-Oncology MDTs in each of the cancer centres will ensure the delivery of a comprehensive hospital-based clinical service, networked with SACT treating hospitals within the hospital group and will provide a supportive link (e.g. education) with community cancer support centres via a 'hub and spoke' model (Appendix 2). Where a Psycho-Oncology MDT exists in a cancer centre (hub) there should be links created with oncology, haematology and psychology teams in SACT hospitals (spokes) within the hospital group, for professional support and advice. If a patient receives treatment outside of a main cancer centre, they will also receive psychosocial support through the 'hub and spoke' model.

The varying degrees of psychosocial distress make it essential that patients are able to access different types of support. The degree of severity experienced by the patient will dictate the level of intervention and expertise required.



Community Cancer Support Centres

Over the past number of years, a substantial number of Community Cancer Support Centres and Services have been established for cancer patients, their families and carers. The services they provide were developed in recognition that cancer patients and their families require on-going psychosocial support during and long after active medical treatment is over. These services are best provided in local communities where they are easily accessible.

There are a variety of support centres and services located nationally, ranging from support groups to full-time professional organisations. Some Community Cancer Support Centres and Services have a range of professionals within their teams, including psychologists, counsellors, oncology nurses, physiotherapists, complementary therapists, etc. (see Appendix 3 for full team composition and ancillary services provided).

Community Cancer Support Centres and services fill a substantial gap in patient services and have been recognised as being an essential part of the cancer journey. Core services provided by many centres are;

- > Oncology Information/Advice,
- > Psychological support; and
- > Survivorship programmes.

Other services provided are transport and complementary therapies.

Community Cancer Support Centres are voluntary and charity organisations and as such receive funding through a number of sources including; fundraising, philanthropy and for a minority, limited public funding.

As part of the NCCP Best Practice Guidance for Community Cancer Support Centres and Services (Greally & Love, 2020), self-assessment and peer-review processes will come into effect in 2021 and subsequently a network of approved centres will be published and available on the NCCP website, and other relevant locations, in 2021. It is envisaged that this development will lead to a more comprehensive service for patients and their families over time.



Who should use the Model of Care

Hospital and Community-based Psycho-Oncology teams should use this Model of Care to guide the development and implementation of their service. Policy makers and healthcare managers should identify gaps in the provision of these services and secure resources to increase capacity to deliver the model of care. Patients with cancer, their families, carers and advocates may be interested in using the Model of Care to understand how services are being provided, what they can expect from service providers and how care will be further developed in the future.

When will the Model of Care be reviewed

It is envisaged that this document will be a living document that will be updated regularly to reflect emerging practice and evidence. A full-scale review of the document will be carried out in 5 years (2025). As reviews take place, any recommended changes will be communicated to all relevant stakeholders and the document will also be updated on the NCCP website.

It is important that the implementation of this Model of Care is evaluated. Consideration will be given to the introduction of key metrics to aid this evaluation and to ensure minimum standards of quality are being met.

Likely outcomes due to a lack of Psycho-Oncology services

In the absence of developing a Model of Care for Psycho-Oncology to facilitate appropriate psychological intervention for patients who require support and based on available evidence, the likely outcomes are:

- Psychological needs left unmet
- Poor adjustment to a diagnosis of cancer
- Lack of engagement or poor adherence by patients to cancer treatments (Mausbach et al., 2015)
- Poorer engagement in survivorship programmes
- Poor coping mechanisms
- More psychosocial support required at a later stage, possibly creating a greater burden on psychological services
- Reduced pain and symptom tolerance or amplification of physical symptoms
- Reduced immunity through the effect of psychological stress, poorer levels of functioning
- Increased hospital admissions (Zebrack et al., 2017) and longer stays (Nipp et al., 2017)
- Increased risk of suicide in patients (Calati et al., 2017)
- Impact on family members and carers (incl. financial distress, unaddressed bereavement issues)

Outcome from deliberations of the working group

Key Values for the Model of Care

The Working Group identified the following key values:

- Weight to be given to the psychological, as well as the physical care aspects of cancer.
- Equal weight to be given to the prevention and early detection of psychological concerns, rather than solely focussing on patients with a higher risk of more severe psychological difficulties.
- A clearly identified referral pathway between the acute, primary and community cancer support, with comprehensive assessment using the 5-level model (see Figure 1) and regular screening and monitoring throughout the cancer journey, as required.
- Routine screening is recommended, where possible and, where there is adequate service for referral. See Appendix 5 – Scoping Questions.
- Address the training and support needs of oncology staff to recognise and evaluate distress in patients during both inpatient stays and their clinical visits.
- Patient collaboration/engagement to ensure that a discussion takes place with every patient in relation to their psychological response to their cancer diagnosis and what extra supports they require, if any.
- Importance of effective communication, education and awareness of psychological health and making patients aware of Psycho-Oncology services available to them.
- Patient awareness that they can access a referral to Psycho-Oncology MDT through the treating team (e.g.) oncology, haematology, radiology, surgery, medical team.
- Equitable access for all (incl. for example patients with disabilities, non-English speaking patients, homeless patients) and flexibility within services provided to adapt to the needs of patients and patient preference (e.g. virtual/telephone consults, if clinically appropriate).
- Tailored evidence-based interventions including individual (one-to-one therapy), group therapy and psycho-education.
- Meeting adequate levels of patient need and assessing gaps in service/support.
- Innovative ways of working, such as offering secure remote counselling services for patients due to the restrictions of COVID-19 or other infectious diseases, or for those who live away from the main cancer centres.
- Importance of psychosocial support to family members and carers.

Core components to the successful implementation and delivery of the Model of Care

- Commitment to the development of Psycho-Oncology services and implementation of the Model of Care by hospital management.
- Assessment of distress by cancer treating team. A list of suggested scoping questions have been developed, however local arrangements may be made to suit each service. In addition the Distress Thermometer can be used (NCCN, Version 2.2020). Every time a member of the treating team meets a patient is an opportunity to discuss the patients' well-being.
- The delivery of this Model of Care requires collaboration between acute, primary and community services, working together to achieve its aim and objectives. By strengthening collaboration with community-based support, Psycho-Oncology teams within cancer centres/hospitals can manage the demand on their services and improve patient flow, which will benefit both the patient and the cancer centre/hospital.
- The enhancement of community services, in a coordinated and integrated manner, to complement and work alongside acute services is crucial to delivering the right care in the right place and at the right time.
- All patients (post-diagnosis; regardless of treatment option offered) should be encouraged to attend a psycho-education information session, which is co-ordinated by the Daffodil Centre nurses in hospitals where there is a centre (e.g.) pre-treatment information session. This will act as both an introduction to the psychological and psychosocial impact of cancer, as well as a signposting service informing patients and their families about available services.
- Similarly, the aim of the end-of-treatment workshop currently in development may be used to address the current gap in service provision for cancer survivors by providing appropriate information and signposting to empower patients, and enhance their quality of life when they have completed active treatment.
- On-going assessment along the cancer care continuum in recognition of changing needs (see Appendix 6). Patients may move backwards and forwards between the five levels of care, as clinical need dictates.
- Training in communication and training in the management of distress for all staff/oncology teams, including when it is most appropriate to introduce Psycho-Oncology services.
- Development & dissemination of information booklets for patients and family members.
- Recognition that each patient's coping skills are unique to them.
- Evaluation of patient experience of their care pathway.
- Facility to offer remote Psycho-Oncology services, if required.

Barriers to the Model of Care

A number of barriers have been identified by the working group that will need to be considered during the implementation phase of the Model of Care. As identified by the National Cancer Strategy 2017-2026 there are gaps and limited capacity in the cancer centres in the number and professional make-up of the multi-disciplinary teams for Psycho-Oncology. There is insufficient capacity in the context of rising demand. Cancer centres will be responsible for the provision of adequate space and the facilities for these teams to work in. Access to infrastructure within cancer centres/hospitals will be needed if Psycho-Oncology MDT staff levels increase (i.e. treatment rooms). This capacity will need to be strengthened and built during the lifetime of the Strategy and the government has committed to doing this. The charity and voluntary sector currently provide a defacto community psychosocial service and this sector needs to be supported and developed as an integral part of the Model for Care.

Access to psychology and psychiatry are needed to provide the full range of Psycho-Oncology services. This and the MDT in cancer centres will require year-on-year resources to build for a sustainable service.

It is critical to promote an understanding of the speciality of Psycho-Oncology and recognition that these services are a vital part of the cancer treatment by all medical professionals. To that end the visibility and promotion of the service, which has an impact on referrals, will also be important. The educational and information needs of both cancer patients, their families and carer, and healthcare professionals will need to be developed. As part of the Model of Care, the NCCP Nursing Education Programme on Psychosocial Support and Care to Cancer Patients will be developed and made available for all nursing staff. Education programmes for doctors and other Allied Health professionals also need to be developed so that all healthcare professionals working with cancer patients can be aware of the unique challenges faced by this group.



New ways of working

The impact of COVID-19 has created significant levels of stress, anxiety, worry and fear for many people. Over the past few months, many innovative and new ways of working have been developed within the healthcare service and will continue to be implemented as the situation continues to evolve. The establishment of remote and virtual access interventions to supplement existing services has changed how we treat patients with mild to moderate, and in some cases, severe psychological distress. A similar response may be required in the future.

T4CC

- The Model of Care is adaptable to new challenges as evidenced from the COVID-19 pandemic. As examples of this, Together 4 Cancer Concern (T4CC), a new service was created as a very rapid response to the emergence of COVID-19 and the realisation of the potential impact on the psychological well-being of cancer patients and their families. It consists of a support line through which the full spectrum of psychosocial interventions can be accessed remotely.
- It provides a full continuum of psychological support to adult and paediatric cancer patients and their families. This is a collaborative partnership between the statutory and voluntary sectors.

Advice for re-opening

- Advice for the safe re-opening of Community Cancer Support Centres was developed by the NCCP (Greally, 2020).
- The guidance in this document is based on national recommendations current at the time of writing, to inform the safe re-opening of support centres in line with the government road map. Of note, current advice should be consulted regularly, to ensure safe delivery of services for staff and clients. NCCP guidance should also be read in conjunction with the Return to Work Safely' protocol from the Health and Safety Authority (HSA), the Health Service Executive (HSE), the Department of Health and the Department of Business, Enterprise and Innovation (Government of Ireland, 2020).

Over the past few months, many innovative and new ways of working have been developed within the healthcare service and will continue to be implemented.

Patient Referral Pathways

Patients need clearly identified trajectories to accessing psychosocial supports from diagnosis onwards (see Appendix 7 for Sample Patient Pathway) and, especially when they are discharged from active cancer treatment (see Figure 2 below for suggested pathway post-discharge from active treatment). Transition from acute services can represent a sudden cessation of regular support for some patients.

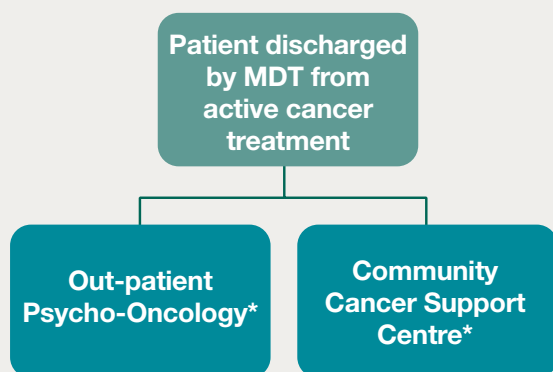
There are various possible avenues to link with psychosocial supports post-discharge, and these will depend on Psycho-Oncology services at the treating hospital, the availability and level of expertise of psychological and counselling services and support in the community and the patient's assessed level of need.

All treating teams should be able to refer to and/or recommend Community Cancer Support Centres, if they so wish, and to ensure the transition from acute to community services is as streamlined as possible for the patient.

It is advised that patients are made aware by their treating team of the various local options available to them to re-access the Psycho-Oncology MDT within a defined time period – usually within three months (see Figure 3 below for suggested pathways).

Patients should be able to easily communicate with their oncology, haematology, or surgical teams to discuss any psychosocial concerns, with the possibility of onward referral to the Psycho-Oncology MDT. Community Cancer Support Centres should also be able to support patients who have previously been seen by the Psycho-Oncology MDT to use locally established referral pathways, to seek re-referral to the Psycho-Oncology MDT, as indicated if the patients' concerns are still cancer-related.

Figure 2. Suggested post-discharge pathways to Psycho-Oncology services

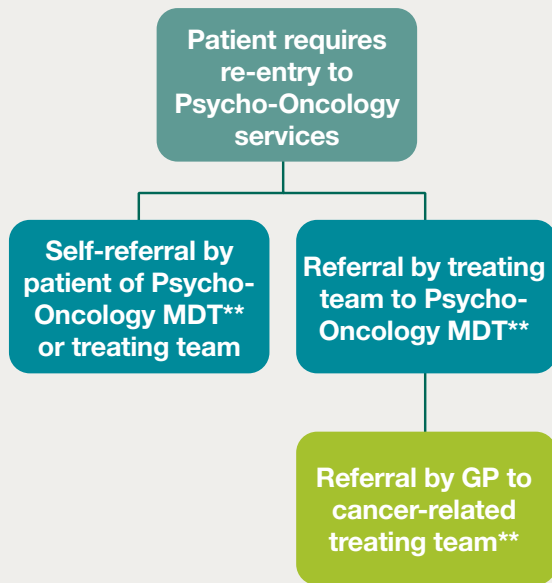


**Depending on level of need and expertise available*

Patients need clearly identified trajectories to accessing psychosocial supports from diagnosis onwards.

Similarly, patients may also need to link back in with acute services if they display high levels of psychological distress, over and above what can be managed in the community setting, and require specialised interventions for symptom management.

Figure 3: Referral pathway back to acute services/ Psycho-Oncology MDT



***If patient is known to them and within a defined time period of three months*

For patients who are not known to the Psycho-Oncology MDT, and display high levels of psychological distress, over and above what can be managed in the community setting, Community Cancer Support Centres should either refer the patient to their GP, who will be able to refer to primary care or Adult Mental Health Services, or encourage self-referral back to their oncology treating team, as appropriate.

The above suggested pathways into and out of acute Psycho-Oncology services are a guideline for Psycho-Oncology MDTs and it is understood that local referral pathways may be in place.

However, it is key that there are indeed local pathways in place and that patients and treating teams are aware of such, so that patients can gain access to appropriate services that best match their level of need.

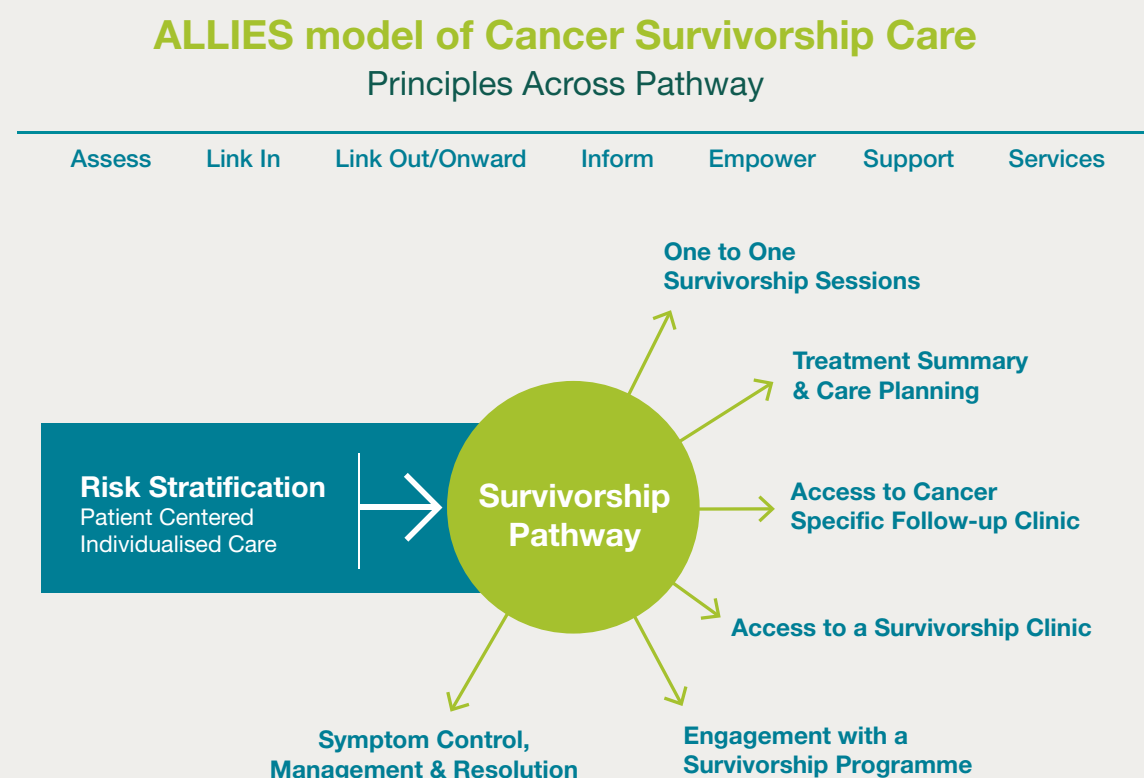
Survivorship Models

While there are many aspects to Psycho-Oncology care provision and meeting the needs of patients and their families within the proposed Model of Care, it is important to highlight the important role Psycho-Oncology services play in survivorship care, palliative care and cancer rehabilitation.

Survivorship services for patients with cancer are one of the key drivers in terms of psychological well-being for cancer patients and their families. Having access to Psycho-Oncology services in hospitals and/or in the community is key to best practice survivorship care. The National Cancer Survivorship Needs Assessment identified the need to build expertise to meet the needs for symptom burden in the physical and psychological domains as one of the priority actions (Mullen and Hanan 2019). A number of actions outlined for implementation include a hospital – community Psycho-Oncology Model of Care.

Healthcare professionals surveyed for the Needs Assessment identified needs in three domains, namely physical, psychological and functional (Hegarty et al., 2018). The proposed ALLIES model for survivorship care (see figure 4) when implemented will contribute towards formalising pathways to treat and manage troublesome symptoms, support individuals to transition through the various stages of the cancer journey and encourage active participation of patients in self-management. This model may be a guide to those developing and providing Psycho-Oncology and survivorship services to those living with and beyond cancer.

Figure 4. ALLIES Model of Cancer Survivorship Care



Cancer Rehabilitation

In recent years, the integration of cancer rehabilitation for physical well-being with Psycho-Oncology care is seen as an important part of holistic care. Cancer rehabilitation should be considered for delivery at all points along the patient pathway. This includes before treatments (prehabilitation), during curative and non-curative treatments and post-treatment. Approaches that address both physical and psychosocial issues can contribute to integrated care and benefits for patients. As an example, the Macmillan Cancer Support's report (2019) emphasised the vital role psychological interventions, alongside physical exercise and diet, has in improving clinical outcomes, improving resilience to the effects of cancer treatments, enhancing the quality of recovery and quality of life.



Palliative Care

There can be many different outcomes following a cancer diagnosis and this is recognised in the Model of Care. Many patients make a full recovery from cancer, others have a long remission and unfortunately some experience a recurrence of their disease at some point following initial treatment. There are also a group of patients for whom their illness progresses to a terminal phase of life and whose needs differ from other cohorts of patients. It is important to recognise one of the core principles of living with cancer, and that is that all patients have a need to live well with cancer, whatever stage they are at. In this regard, there needs to be recognition that timely referral to Palliative Care services is an important Quality of Life issue for these patients and their families. The National Clinical Programme for Palliative Care recently published the Adult Palliative Care Services Model of Care for Ireland (Ryan, 2019) and this should serve as a roadmap for services for these patients.

It is important to recognise one of the core principles of living with cancer, and that is that all patients have a need to live well with cancer, whatever stage they are at.

What implementation of the Model of Care will mean

- Ensure patients and their families have a positive experience of care
- Access to appropriate assessment, support and intervention for psychosocial distress
- Improved wellbeing and quality of life
- Improved clinical outcomes
- Clear pathway to services in both the acute and community settings
- Improved psychological skills and understanding across all members of treating team
- Impact on wider healthcare utilisation and potential cost savings
- Integrated team working
- Advancement of recommendations in the National Cancer Strategy and Sláintecare's goals
- Implementation of Psycho-Oncology education nationally for all registered nurses, involved with cancer care delivery.

Conclusion

In conclusion, the Psycho-Oncology Model of Care (2020) expands and formalises many of the key recommendations contained in the National Cancer Strategy 2017 – 2026. It provides a road map for the key aspects of the strategy and looks forward to the continued development of Psycho-Oncology services for cancer patients and their families. It also highlights crucial aspects for patients including moving from one service to another (e.g.) transitioning from acute hospitals to community support, barriers to psychosocial care and the importance of a collaborative approach to services. It is very much focused on the Sláintecare model of 'the right care, in the right place at the right time'.



Key Recommendations

- 1.** Establish Psycho-Oncology Multi-Disciplinary Teams in all cancer centres.
- 2.** Screen for distress for all patients with cancer, as per Appendix 5, followed by a comprehensive evaluation of individual patients needs and referral to the appropriate type, setting, and level of service.
- 3.** Minimum of two points of assessment of distress throughout the cancer journey.
- 4.** Recognise the psychological and social impact of a cancer diagnosis on family members and carers.
- 5.** A representative from the Psycho-Oncology MDT should attend the weekly Oncology and Haematology MDMs, where appropriate, to ensure there is liaison between medical and Psycho-Oncology teams. Oncology, Haematology and Psycho-Oncology MDTs to facilitate communication and information about the psychosocial supports that are available for patients, in both treating hospitals and Community Cancer Support centres.
- 6.** Survivorship programmes should be available and accessible to help cancer patients and their families adapt to living with and beyond cancer.
- 7.** NCCP Nursing Education Programme on Psychosocial Support and Care to Cancer Patients to be made available for all nursing staff.
- 8.** Education Programmes on Psychosocial Support and Care to Cancer Patients to be developed for all healthcare professionals.

References

Calati, R., Di Mattei, V. and Courtet, P., (2017) Risk of suicide mortality among cancer patients: A meta-analysis of observational studies. *European Psychiatry*, 41, pp.S290-S291. Available at: <https://doi.org/10.1016/j.eurpsy.2017.02.157>.

Carlson, L.E. & Bultz, B.D. (2003). Benefits of psychosocial oncology care: Improved quality of life and medical cost offset. *Health & Quality of Life Outcomes*; 17: 1-8. Available at: <https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-1-8>.

Cho Y, Jeon Y, Jang S, et al. (2018). Family members of cancer patients in Korea are at an increased risk of medically diagnosed depression. *Journal of Preventative Medicine & Public Health*; 51: 100-108. Available at: <https://doi.org/10.3961/jpmph.17.166>.

Department of Health (2017). National Cancer Strategy 2017-2026. Available at: <https://assets.gov.ie/9315/6f1592a09583421baa87de3a7e9cb619.pdf>.

Department of Health (2020). Sharing the Vision: A Mental Health Policy for Everyone. Available at: <https://www.gov.ie/en/publication/2e46f-sharing-the-vision-a-mental-health-policy-for-everyone/>.

Forsythe, L.P, Kent, E.E., Weaver, K.E., et al. (2013). Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology*; 31: 1961-1969. Available at: <https://ascopubs.org/doi/10.1200/JCO.2012.46.2101>.

Greally, H. (2020). Advice to inform the safe re-opening of Community Cancer Support Centre's. National Cancer Control Programme: Dublin. Available at: <https://www.hse.ie/eng/services/list/5/cancer/news/safe%20re-opening%20of%20cancer%20support%20centres.html>.

Greally, H. & Love, D. (2020). NCCP Best Practice Guidance for Community Cancer Support Centres and Services. National Cancer Control Programme: Dublin.

Hegarty J., Murphy A., Hanan T, O' Mahony M., Landers M, McCarthy B., Lehane E., Noonan B., Fitzgerald S., Reidy M., Saab M.M., Corrigan M., Mullen L. (2018). Acute Sector Cancer Survivorship Services in the Irish Context. National Cancer Control Programme; Dublin.

Holland, J. & Alici, Y. (2010). Management of distress in cancer patients. *The Journal of Supportive Oncology*: 8; 4-12.

Layard, R. & Clarke, D.M. (2014). *Thrive: The Power of Psychological Therapy*. Penguin Books, London.

Macmillan Cancer Support. (2019). Prehabilitation for people with cancer: principles and guidance for prehabilitation. Available at: <https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf>.

Mausbach BT, Schwab RB, Irwin SA. Depression as a predictor of adherence to adjuvant endocrine therapy (AET) in women with breast cancer: a systematic review and meta-analysis. *Breast Cancer Research and Treatment*; 152:239-246.

Mullen, L. & Hanan, T. (2019). National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland. National Cancer Control Programme: Dublin. Available at: <https://www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/living%20with%20and%20beyond%20cancer%20in%20ireland.pdf>.

National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Distress Management. Version 2. Fort Washington: NCCN; 2020.

Pirl WF, Fann JR, Greer JA, et al. (2014). Recommendations for the implementation of distress screening programs in cancer centers: report from the American psychosocial oncology society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer*; 120(19): 2946-2954.

Ryan, K. (2019). Adult Palliative Care Services Model of Care for Ireland. National Clinical Programme for Palliative Care: Dublin. Available at: <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf>.

Schouten B, Avau B, Bekkering GTRUDYE, Vankrunkelsven P, Mebis J, Hellings J, Van Hecke A. Systematic screening and assessment of psychosocial well-being and care needs of people with cancer. *Cochrane Database of Systematic Reviews* 2019, Issue 3. Art. No.: CD012387. DOI: 10.1002/14651858.CD012387.pub2.

Sklenarova H, Krumpelmann A, Haun M, et al. (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*; 121(9); 1513-1519. Available at: <https://doi.org/10.1002/cncr.29223>.

Smith SK, Loscalzo M, Mayer C, Rosenstein DL. (2018). Best practices in oncology distress management: beyond the screen. *Am Soc Clin Oncol Educ Book*; 813-821.

Smith, T.G., Troeschel, A.N., Castro, K.M. et al. (2019). Perceptions of patients with breast and colon cancer of the management of cancer-related pain, fatigue, and emotional distress in community oncology. *Journal of Clinical Oncology*, 37: 1666-1676. Available at: <https://doi.org/10.1200/JCO.18.01579>.

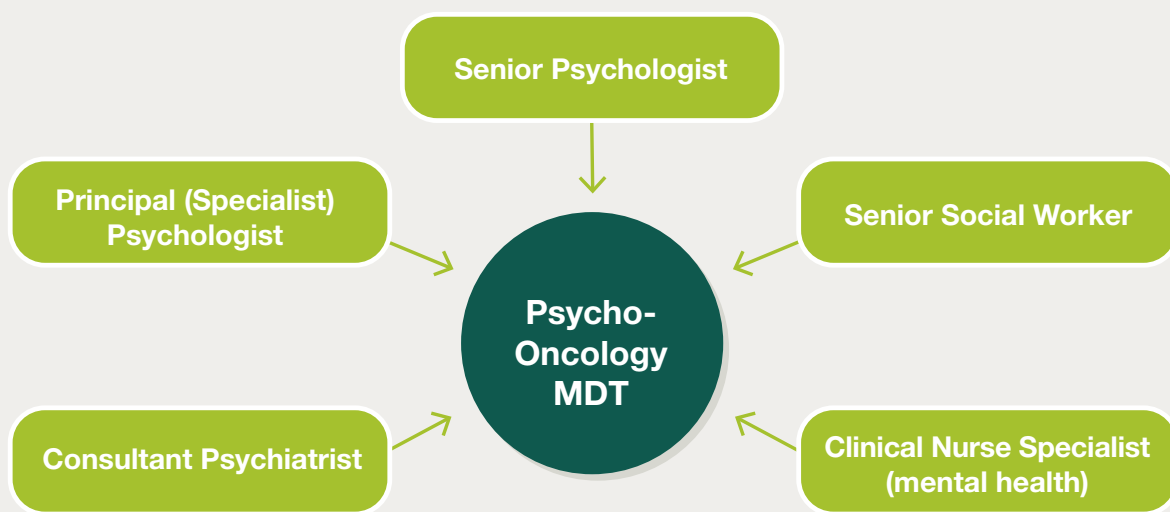
Wen S., Xiao H., Yang Y. (2019) The risk factors for depression in cancer patients undergoing chemotherapy: a systematic review. *Support Care Cancer*; 27 (1): 57-67.

Zebrack, B., Kayser, K., Bybee, D., et al. (2017). A practice-based evaluation of distress screening protocol adherence and medical service utilisation. *Journal of the National Comprehensive Cancer Network*; 15(7): 903-912. Available at: <https://doi.org/10.6004/jnccn.2017.0120>.

Appendix 1

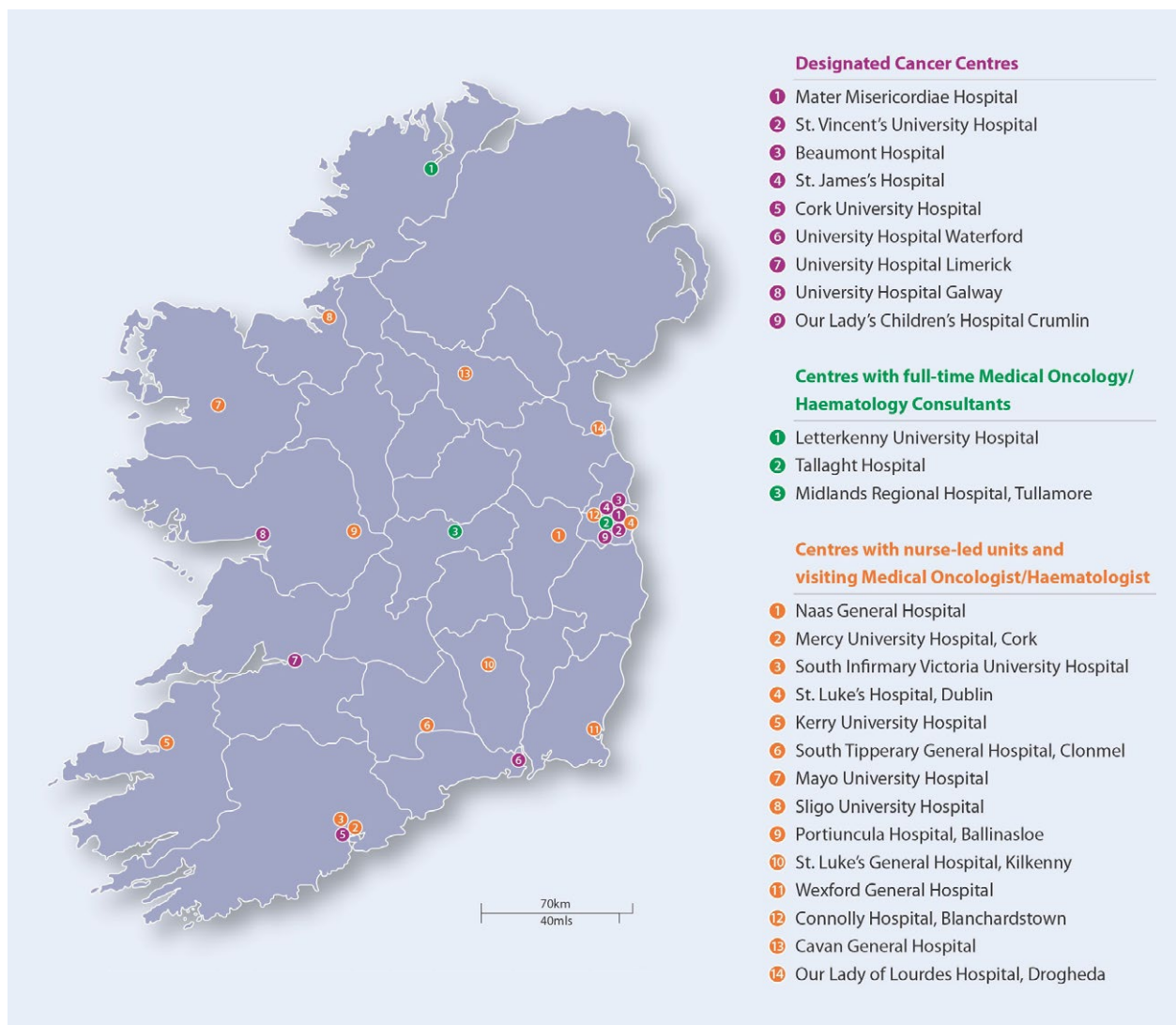
Psycho-Oncology MDT composition

Psycho-Oncology team composition, as recommended in the National Cancer Strategy (2017-2026).



Appendix 2

Hub & Spoke model for the delivery of medical cancer services



As part of the NCCP Best Practice Guidance for Community Cancer Support Centres and Services (Greally & Love, 2020), self-assessment and peer-review processes will come into effect in 2021 and subsequently a network of approved centres will be published and available on the NCCP website, and other relevant locations. It is envisaged that this development will lead to a more comprehensive service for patients and their families over time.

Appendix 3

Community Cancer Support Centres & Services - Team Composition

Team composition is dependent on the size and scope of the services offered by each centre and may include any or all of the disciplines below:



Ancillary services

- › Complementary therapies
- › Manual Lymphatic drainage
- › Benefits advice
- › Yoga classes
- › Tai-Chi classes
- › Art classes
- › Bereavement support group
- › CLIMB programme for children
- › Nutrition advice
- › Mindfulness programmes
- › Exercise programmes (e.g.) Strides for Life
- › Stress Management programmes
- › Cancer Thriving and Surviving Programme
- › General and/or site-specific cancer support groups

(subject to change due to COVID-19)

Appendix 4

Membership of the Psycho-Oncology Model of Care working group

Name	Title	Organisation
Dr Helen Greally (Chair)	National Clinical Programme Lead for Psycho-Oncology	NCCP
Ms Louise Mullen	National Lead for Cancer Survivorship	NCCP
Ms Terry Hanan	National Clinical Lead for Cancer Nursing	NCCP
Ms Deirdre Love	Project Manager for Psycho-Oncology & Cancer Survivorship	NCCP
Ms Cathleen Osborne	Assistant Director of Nursing	NCCP
Ms Lisa Marry	CNM3 Nursing Projects Manager	NCCP
Ms Bernie O’Loughlin (from Feb 2020)	Survivorship Programme Co-ordinator	NCCP
Ms Pauline Robinson (from Feb 2020)	Assistant Director of Nursing, Cancer Survivorship	NCCP
Dr Una Kennedy	GP	NCCP GP
Dr Sonya Collier	Principal Clinical Psychologist	St James’s Hospital
Dr Sinead Mulhern	Principal Clinical Psychologist Manager	Mater Hospital
Dr Natalie Hession	Head of Psycho-Oncology Services	SLRON
Dr Norma-Jean Murphy	Senior Clinical and Counselling Psychologist	Cancer Care West, Galway
Dr Chiara Besani	Principal Clinical Psychologist (Paediatrics)	Our Ladies Childrens Hospital, Crumlin
Dr Greg Leonard (until June 2020)	Consultant Medical Oncologist	Galway University Hospital
Dr Tara Kingston	Consultant in Liaison Psychiatry	St James’s Hospital
Ms Catherine Marron (until May 2020)	Senior Medical Social Worker	St James’s Hospital
Ms Julie O’Shea (from May 2020)	Senior Medical Social Worker	Beaumont Hospital
Ms Dorothy Thomas	Community Support Network Co-ordinator	Irish Cancer Society

Membership of the Psycho-Oncology Model of Care working group

Name	Title	Organisation
Ms Rachel Morrogh	Director of Advocacy and External Affairs	Irish Cancer Society
Ms Aileen Emery	Director of Services	Gary Kelly Cancer Support Centre, Drogheda
Ms Sinead Quinn	Patient advocate	
Ms Ciara Morris	Patient advocate	DoH Cancer Patient Advocacy Group
Mr PJ Rainey	Area Director of Mental Health Nursing and member of DoH Cancer Patient Advisory Group	HSE
Ms Jennifer Carpenter	Service Manager	Hand-in-Hand
Ms Fiona O'Connor Power	Assistant Director of Public Health Nursing	South Dublin Community Intervention Team

Appendix 5

Scoping questions for assessing distress

The following scoping questions have been suggested by the working group to aid the standardisation of screening and to encourage discussions about distress. They should be used at the discretion of the professional.

- > How are you feeling today?
- > How are you coping?
- > How long have you been feeling that way?
- > What is your biggest concern?
- > Is your concern related to your cancer?
- > What might help right now?
- > Is there anyone (friends/family/cancer support services) that you can call on for support?
- > What is important to you at the moment?
- > Is this something you need or want help with?

Appendix 6

Assessment points

Good clinical practice states that assessment should be an on-going process. It is suggested that assessments be carried out at key transition points in the patient pathway (at the discretion of the treating team), for patients identified as having psychosocial distress.

1. At the time of diagnosis

2. Start of treatment

3. During treatment

4. Before discharge from active medical treatment (i.e.) when scheduled treatment plan finishes (e.g. end-of-treatment workshop)

5. Transition to survivorship

6. At recurrence or progression of disease

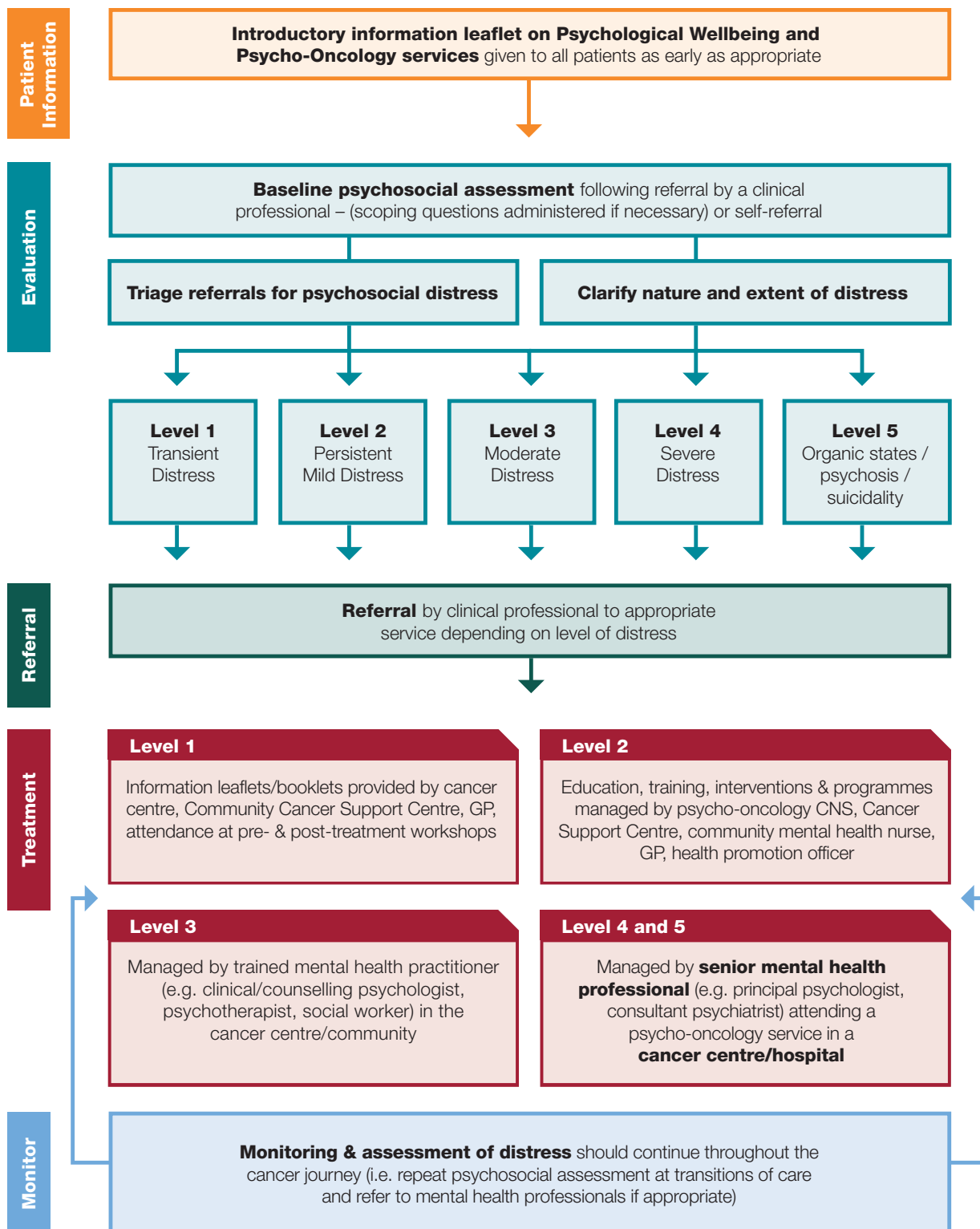
7. At end of life (in conjunction with palliative care services)

8. At any time that the patient self identifies as having difficulties coping with their diagnosis.

There should be a minimum of **two** assessment points.

Appendix 7

Proposed Patient Pathway





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