

NATIONAL

# PALLIATIVE CARE STRATEGY

FOR MALTA

2025-2035



## **ACKNOWLEDGEMENTS**

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## FOREWORD

Malta has one of the highest rates of life expectancy at birth in the EU and while this is a positive indicator of the overall health of the country, it brings about new challenges which must be addressed by the healthcare sector. Medical advancements have transformed previously fatal conditions into chronic ones, while the survival rate of chronic conditions has increased too. This results in a greater proportion of the population living with the burdens of one or more chronic illnesses for a longer period. A greater population base requiring palliative care is therefore expected.

Palliative care improves the quality of life of patients with chronic debilitating illness or conditions as well as their families' experiences. Our target is to address palliative needs and integrate palliative care as early as possible in one's chronic illness journey and our new Palliative Care Strategy aims to do just this. By addressing all aspects of care and support including social, psychological and physical symptoms, care and human dignity is ensured at all stages of the illness regardless of the person's age and diagnosis.

This strategy focuses on the need to increase and develop the healthcare workforce in the field of palliative care, by providing more opportunities of specialization in this field and by creating multidisciplinary palliative care teams. The latter is a new concept which will address patients' hospital and community needs. This team will be available to offer patients, and their families, specialist advice at all levels of care round the clock. Increased in-patient facilities will in turn require increased bedspace available for palliative care, which is also addressed by this Strategy and is backed by the Government's financial commitment.

Our intention is to offer high quality integrated palliative care services to improve the patient's quality of life, dignity and comfort. This strategy will showcase our determination and vision to address the challenges ahead.

We would like to take this opportunity to thank all the healthcare workers who dedicate their professional career to palliative care and to all those who are yet to be recruited to strengthen our palliative services. Your dedication and care make a big difference.

## EXECUTIVE SUMMARY

Palliative care is an integral part of the care delivered by all health and social care professionals, as well as by families and carers, to those living with, and dying from any chronic, debilitating disease. Palliative care aims to improve the quality of life by using a holistic approach to addressing not only the physical symptoms associated with the patient's condition, but also the emotional, psychological, spiritual, social and economic consequences.

The purpose of this strategy is to set the direction and guide change with respect to palliative care in Malta for the 10-year period 2024 – 2034. Being the first palliative care strategy for Malta, the plan is comprehensive and ambitious, and its implementation will be carried out gradually according to a detailed action plan delineating which initiatives shall be considered for implementation in the short-, medium- and long-term.

Our vision is to provide access to high quality, integrated palliative care for all patients who need it; and to maintain and improve their quality of life, dignity and comfort throughout the course of their illness, irrespective of diagnosis and care setting. As an integral part of palliative care, the strategy sets out support for patients' families and carers throughout the care trajectory, both during the illness and after the loss of their loved one. In line with this vision, the strategy seeks to meet the needs of patients living with cancer, other chronic debilitating diseases such as organ failure and rare diseases, as well as frailty and dementia. The strategy sets out care provision across all settings where palliative care can be provided including people's own homes, nursing homes and other long-term care facilities, general hospital wards and specialist palliative care settings. Whilst the strategy focuses on adult palliative care services, it also acknowledges the specific needs of children and young people requiring palliative care, together with their parents and families.

Through the various recommendations being proposed, the strategy seeks to raise awareness and understanding about palliative care and end-of-life care using a public health approach by addressing the concerns of the public, and importantly, the professionals delivering palliative care. Recommendations will strengthen and develop high quality, integrated palliative care services at all levels of care, from specialised palliative care units or hospices, to care at the community level including care provided in patients' own home. Due consideration is being given to strengthening community-based palliative care services and the integration of palliative care delivered in the acute hospital settings. A compassionate, skilled, knowledgeable, and competent workforce is fundamental to the development of high

quality, integrated palliative care services and is considered as a fundamental building block on which implementation of other initiatives will depend.

The strategy reinforces the need to work in collaboration with all relevant stakeholders Governmental and non-Governmental, both within and outside the health sector. Valuing the lived experience of people receiving palliative care, their families and carers is also considered essential to truly develop services that meet their needs.

## **LIST OF ABBREVIATIONS**

A&E – Accident & Emergency

CPD – Continuing Professional Development

EAPC – European Association for Palliative Care

ECEPC - European Certificate in Essential Palliative Care

GGH – Gozo General Hospital

GP – General Practitioner

GSF - Gold Standards Framework

LCP - Liverpool Care Pathway for the Dying Patient

LOS – length of stay

MAU - Medical Assessment Unit

MDH - Mater Dei Hospital

NACPC – National Advisory Committee on Palliative Care

NPICU – Neonatal Paediatric Intensive Care Unit

PCU - Palliative Care Unit

RHKG – Rehabilitation Hospital Karin Grech

SACT - Systemic Anti-Cancer Therapy

SAMOC - Sir Anthony Mamo Oncology Centre

SPICT - Supportive & Palliative Care Indicators Tool

SVPR - Saint Vincent De Paul Residence

## OPERATIONAL DEFINITIONS

In order to ensure clarity, accuracy and consistency, the following definitions are adopted for use in this strategy:

### a. WHO Definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (1)

### b. End-of-life care

End-of-life care is often used synonymously with palliative care or hospice care. End-of-life care may be understood more specifically as comprehensive care for dying patients in the last few hours or days or weeks of life (2,3)

### c. Hospice care

Hospice care is a term that is often used to describe the care offered to patients when the disease process is at an advanced stage. The term may be used to describe both a place of care (i.e. institution) or a philosophy of care, which may be applied in a wide range of care settings (4).

Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi- professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace and calm (2,3).

**d. Terminal care**

Terminal care is an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy (2). Terminal care is a continuum of palliative care and it usually refers to the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less (4).

**e. Respite care**

Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break (2,3).

**f. Specialist palliative care**

Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multi- professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care (2,3).

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# 1. Chapter 1 - Background

## 1.1. The concept of palliative care

" You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders, founder of the modern hospice movement.

Modern medicine, particularly in developed countries, has become especially focused on the provision of highly sophisticated and costly health care with curative intent, and the development of new, expensive, medical techniques and medicines. However, this type of health care has been recognised as failing to meet the basic needs of people living with chronic, debilitating diseases. This is where the value of palliative care comes in and is considered as an essential component of appropriate health care based on human dignity, autonomy, human rights, patient rights and a generally acknowledged perception of solidarity and social cohesion (5).

Palliative care aims to improve the quality of life of persons living with chronic, debilitating diseases, together with their families and carers, by taking a holistic approach to addressing physical symptoms associated with their condition, but also the emotional, psychological, spiritual, social and economic consequences. Palliative care is thus fundamental to human dignity and is an expression of the fact that dignity should be respected throughout a person's life until his or her natural death (6). Ultimately, the main aim is for patients to live as well as possible, for as long as possible.

Historically, palliative care addressed the needs of people with cancer, for a specific time frame, mainly the end-of-life stage. Today it is widely acknowledged that palliative care should be provided to a range of conditions, irrespective of age and diagnosis. Conditions in which palliative care may have a role include non-communicable chronic diseases such as cancer, cardiovascular diseases, chronic obstructive pulmonary disease, kidney failure, chronic liver disease, rheumatoid arthritis, neurological diseases, Alzheimer's disease and other dementias, congenital anomalies, as well as infectious diseases such as HIV/AIDS<sup>1</sup> and drug-resistant tuberculosis (7). Furthermore, palliative care can be beneficial at an earlier stage than the period when death is imminent and should be considered earlier on in the illness trajectory (8). Palliative care should be integrated at all levels of health care, starting from the patient's own home, to hospitals and specialised palliative units (9).

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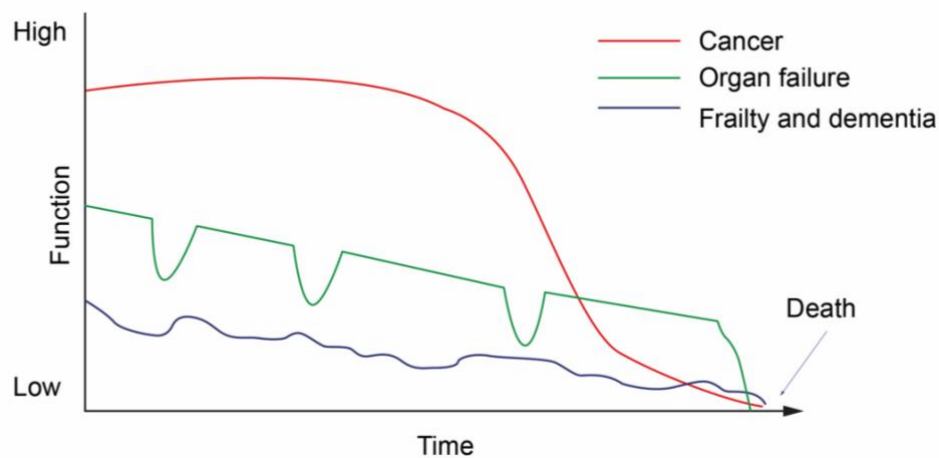
<sup>1</sup> In the past, palliative care had a greater role in the management of HIV/AIDS, but increasingly the focus has moved to providing appropriate anti-retroviral treatment, thus almost obviating the need for palliative care services in this situation (6)

### 1.1.1. Different disease trajectories and implications for care

Three typical disease trajectories have been described for people with progressive chronic illness: cancer, organ failure (e.g. respiratory and heart failure), and the frail elderly or dementia (Alzheimer's disease) trajectory. Physical, social, psychological, emotional and spiritual needs of patients and their carers vary according to the trajectory they are following (10,11). Figure 1 provides a pictorial view of these three disease trajectories while table 1 also summarises the differences between these trajectories and the implications for the development and delivery of palliative care.

Evidence suggests that cancer patients are more likely to receive palliative care than people with a non-cancer diagnosis. This may be due to the predictability of health decline and the fact that historically, hospice care was aimed for people with cancer only (12,13). There is a need to address these inequalities in access to palliative care and to address the unmet needs of all people suffering from all chronic life-threatening or life-limiting illnesses.

**Figure 1: The three main disease trajectories denoting health decline towards the end-of-life**



Adapted from Lynn & Adamson, 2003 (11) and Murray et. al. 2005 (10)

**Table 1: Differences between the three main disease trajectories (cancer, organ failure, frailty and dementia) towards the end-of-life**

Characteristic	Cancer	Organ failure	Frailty and dementia
Trajectory	Progressive, accelerating deterioration	Unpredictable, with exacerbations and recoveries	Slow, progressive deterioration; sudden changes rare
Treatment	Curative/life-prolonging therapy often stopped at the time of transition to palliative care	Disease-modifying therapies provide symptom control; usually continued even for palliation	Treatment primarily supportive
Prognostication	Well-recognized syndromes or functional decline associated with prognosis < 6 months	Prognostication challenging, especially beyond 3 months; patients with “end- stage” disease can survive for years on life-sustaining therapies (e.g., dialysis)	Prognostication challenging; no reliable models for identifying final months
Needs/concerns	Pain/symptom control; fear of death; social and physical supports typically needed only in final weeks or months	Symptom control; decisions about life-sustaining therapies for organ failure (e.g., ventilation, dialysis, organ transplant); needs for social and physical supports often long standing	Functional decline and cognitive impairment; symptoms variable
Typical patient demographics	Age 45–75 years; often family caregiver	Age 70–85 years; partner more likely to be deceased, or elderly and unable to provide support	Age ≥ 75 years; partner more likely to be deceased, or elderly and unable to provide support
Typical patient location	Community dwelling, with increasing visits to acute medical facility;	Community dwelling, with frequent visits to acute medical facility;	Often residents of assisted-living or long-term care facilities; less frequent visits to acute medical facility;

Taken from Rocker et al. 2016 (14)

## 1.2. Economic considerations

Investment in palliative care services, as in any other area, can only be justified if it is deemed as being overall cost-effective. Evidence suggests that developing better strategies for care close to end-of-life may help to reduce the high costs associated with caring for older people. The introduction of timely palliative care may prevent unnecessary medical tests, treatments and interventions which may not only improve quality of life but also save costs (15). There should be robust evidence to support the services and treatments offered aimed at improving patient outcomes. These should also represent good value for money. There is an ever-growing body of evidence suggesting that palliative care can improve the quality of life of patients and reduce health system costs and resource utilization, thus making the healthcare system more efficient (16–18).

When evaluating palliative care from a health economics point of view, one must consider the impact of both inpatient and community-based services, since they are interlinked, and one will influence the results and outcomes of the other. Evidence shows that investing in community services tends to be more cost-effective, in terms of reduced hospital admissions and length of stay, and improves patient outcomes (16).

When carrying out economic evaluations for palliative care and taking decisions based on the results of these evaluations, policy makers need to keep in mind the indirect and often unmeasured or unmeasurable costs and benefits, incurred or gained, by the patient's carers. These costs need to be given their due importance even though and especially because they are in general not always easily captured and quantifiable in such evaluations.

### **1.3. Policy context at the European and International levels**

In 2003, the Committee of Ministers of the Council of Europe adopted Recommendation Rec(2003) 24 (19), on the organisation of palliative care, which constitutes a strong political commitment from the Member States to the development of palliative care services of the highest possible standards. The recommendation defines palliative care as an "integral part of the health care system and an inalienable element of a citizen's right to health care". It therefore considers that "it is a responsibility of the government to guarantee that palliative care is available to all who need it".

The Parliamentary Assembly of the Council of the European Union, in Resolution 1649 (2009) (20) and Resolution 2249 (2018) (21) on palliative care, further stress that palliative care is fundamental to human dignity and a component of the human right to health. It emphasises that palliative care should be available not just to the terminally ill, but also to those who are chronically ill and to persons requiring high levels of individual care who would benefit from a palliative care approach.

Palliative care is also an important component of the Sustainable Development Goals agenda and it is deemed that countries cannot meet Goal 3, Target 3.8 of the Sustainable Development Goals on achieving universal health coverage, without including adequate palliative care and pain relief (6).

In 2007, WHO released the first guide on planning palliative care services for people living with advanced stages of cancer (22). Furthermore, in 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19 (9), called upon WHO Member States to strengthen and improve access to palliative care as an integrated, core component of the health care system, with an emphasis on primary health care and community/home-

based care services. Further palliative care policy documents have been developed by the WHO including guidelines on planning and implementing palliative care services and on implementing palliative care and symptom relief into primary care (7,23).

#### 1.4. Policy context at the local level

This strategy addressing palliative care is the first of its kind for Malta and builds on a number of key documents that have been published in recent years. These include:

- The National Health Systems Strategy for Malta (2014-2020) (24), as well as the recently published National Health Systems Strategy for the period 2023-2030 (25), identify palliative care as an area necessitating strengthened community palliative care services, improved access to non-cancer patients and enhanced knowledge and skills amongst health care professionals.
- The National Cancer Plan for the Maltese Islands (2017-2021) that acknowledges the importance of palliative care as an essential and integral component of cancer care. It highlights the need for a comprehensive national needs assessment for both cancer and non-cancer patients, addressing services and the palliative care workforce, in order to enhance current provision of palliative care (26).
- Patient's Charter – Charter of Patient's Rights and Responsibilities which stipulates that patients have a right "to expect end-of-life care that is dignified, comforting and supporting relief from any unnecessary suffering" amongst other rights and responsibilities also relevant to palliative care (27).
- Consensus document: as part of an Erasmus+ project of the Bioethics Research Programme of the Medical School, on harmonisation of end-of-life care (EndCare) 2018 that comprises a set of guidelines addressing the complex ethical dilemmas surrounding end-of-life care issues which health care professionals face during the exercise of their profession (28).
- Empowering Change: A National Strategy for Dementia in the Maltese Islands 2015-2023 that includes amongst others, a set of recommendations on the provision of palliative care for dementia patients, from diagnosis until death (29).
- National Strategic Policy for Active Aging 2014 – 2020 (30) and the recently published version for the period 2023-2030 (31) which take a holistic approach to addressing the needs of older persons in our society including health care and palliative care.

- Freedom to live: Malta's 2021 – 2030 National Strategy on the Rights of Disabled Persons (32) which includes amongst others, recommendations to address issues related to the provision of and access to health care.

## **1.5. Developing the Palliative Care Strategy for Malta**

An initial consultation process was carried out with key stakeholders, including a focus group with patients and another focus group with relatives of persons receiving palliative care. This was done to map out all existent services and initiatives in relation to palliative care, identify the gaps and limitations in the current services, and gauge what the key priorities for change should be.

Concurrently, a literature review was carried out in order to ensure an evidence-based approach to the development of the strategy. Indeed, this strategy is in alignment with the above-mentioned international recommendations, resolutions and guidelines (section 1.3), as well as the key local strategies and policies (section 1.4). In addition, it has also been informed by a number of seminal documents and strategies from other countries that have been at the forefront in the development of palliative care services (3,33–38).

A formal and wider public consultation process was carried out from February to March 2023. All feedback was analysed, systematically discussed by the working group, and taken into consideration in the compilation of the final strategy document.



## 2. Chapter 2 – Situation Overview

### 2.1. Demographic and social changes; their implications for the provision of palliative care

The population of Malta is aging and following similar trends seen in other European and developed countries (39). Increased longevity is in part due to improved nutrition and sanitation, and advancements in the medical sector that have changed previously rapidly fatal illnesses into chronic diseases. Indeed, the average life expectancy at birth in Malta for those born in 2020 was 82.3 (40) which is higher than the EU average of 81.3 years for 2019 (41). While this is a positive outcome, it is also crucial to consider whether these extra years of life gained through increased longevity are spent in good health since this has a direct impact on the quality of life. According to the State of Health report 2019, Maltese people spend a considerable fraction of their lives in good health, with two thirds of life after age 65 spent without chronic diseases and disabilities, which is a far higher share than the EU average (42). However, this still leaves an increasing proportion of the population living for many years with the symptom burden of one or more serious illnesses, functional or cognitive impairment, mental or emotional distress and dependent on care from family and/or society.

The population of Malta stood at 516,100 at the end of 2020 with a 18.9% share of the population aged over 65 (40). This section of the population carries the highest disease burden in terms of incidence and mortality from cancer and other chronic conditions. As a result of the growing and aging population, over time, increasing number of people will require more complex care for longer, raising the demand for health and social care services in general including that for palliative care services (15).

The above population estimates do not take into consideration the influx of economic migrants, mostly in the 15-44-year age group, that Malta has been experiencing over the past 8 years (43). Since one cannot predict how many of these migrants will remain living in Malta in the future, it is difficult to estimate the long-term impact that these migrants will have on the future demand for palliative care. Nonetheless, it is imperative to acknowledge that Maltese society is becoming increasingly multicultural with consequent implications for health care services, including those for palliative care, to become more culturally sensitive.

Societal structures are also changing. Families have become smaller and more dispersed as a result of various factors such as increased migration, separation or divorce and other external pressures (44). Women who traditionally took up the vast majority of the caring roles in cases of illness in the family (45) are increasingly entering and remaining in the labour market throughout their adult life course. As a result, the numbers of informal carers available to provide support and care for their loved ones who may be living with serious illnesses and nearing end-of-life is decreasing. This is creating further pressure on the health and social care

systems to provide effective and compassionate care for larger numbers of people requiring palliative care services and nearing their end-of-life.

## 2.2. Estimating the need for palliative care in Malta

Research and evidence on palliative care in Malta is very sparse and limited. However, routine mortality data from the National Mortality Registry and National Cancer Registry reveals some important and useful trends and statistics:

- During the period 2014 to 2017 there was an average of 3400 deaths annually. There has been an increasing trend in the number of deaths over the past 20 years (1998-2017) due to population growth over the years. However, the crude mortality rate (total number of deaths divided by total mid-year population) has remained the same reflecting that the proportion of deaths per year has remained stable over the years (46).
- Cardiovascular diseases were the leading cause of death comprising 36.7% (1248) of the average total deaths in 2014-2017. These included mainly deaths due to ischaemic heart disease, heart failure and stroke (46).
- Cancers were the second leading cause of death accounting for 27.8% (945) of the average total deaths in 2014-2017. In 2017 there were 2253 new cases of cancer among the Maltese population, of which 1109 were male, and 1144 were female (47).

Similar to international trends, cancer incidence in Malta is on the increase and predicted to rise by 22.5% to 915/100,000 population in 2030 (48). This means that more people will be living with cancer due to increased incidence, earlier diagnosis, improved treatment and longer survival; and dying from cancer leading to increased need and demand for palliative care in the oncological sector.

- Diabetes accounted for 5% (171 deaths) of the average total deaths in 2014 – 2017 (46) and it is an important risk factor for circulatory diseases. Mortality rates from diabetes in Malta are the third highest in the EU (42).
- Dementia which is an important cause of death in the elderly accounted for 5% (175 deaths) of the average total deaths in 2014 - 2017 (46). This figure could be an underestimation in view of possible shortcomings in cause of death certification by doctors. The burden of disease due to dementia is set to increase given the aging population.

- 68.6% (2336 deaths) of the average yearly deaths in 2014 to 2017 were from conditions considered as having associated palliative care needs, of which 40.5% (945) were from cancer and 59.4% (1391) were from non-cancer conditions namely: cardiovascular diseases, respiratory, renal and liver failure, and neurodegenerative diseases (46).

Not all people dying have palliative care needs. International research studies have revealed various estimates for the need for palliative care which may vary according to the method of estimation used. For instance, according to the European Association for Palliative Care (EAPC), 40% of non-cancer patients and 60% of cancer patients need palliative care (2). An Australian working group estimated the population in need of palliative care to be between 50% and 89% of all dying patients (49). A multi-national study across 12 European and non-European countries, estimated that the proportion of people who died and potentially had palliative care needs ranged from 38% to 74% (50).

According to the EAPC Atlas of palliative care published in 2019<sup>2</sup>, in Malta there were 1902 people in need of palliative care at end-of-life, representing approximately 60% of yearly deaths. Of these, 821 were cancer patients and 431 were people suffering from cardiovascular diseases with palliative care needs, representing 90% and 35% of total yearly deaths from those conditions respectively (39).

### 2.2.1. Place of death

International literature shows that many patients desire to experience their last phase of life at home, although dying in a hospice is another highly preferred option (51–53). Little is known about the expectations and preferences of the Maltese population since no local large-scale population-based studies have been conducted on the matter.

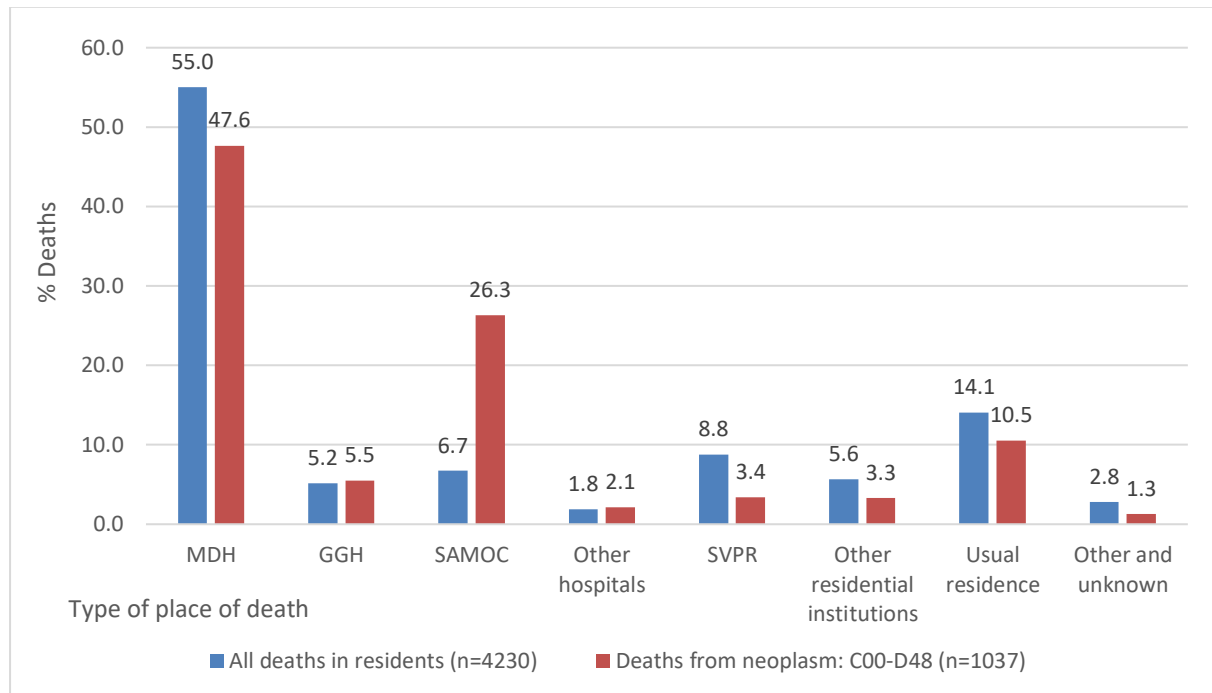
An analysis of deaths by place of death using data from the National Mortality Register indicated that most deaths occur in the acute hospital setting namely MDH (figure 2). A closer look at deaths specifically due to cancer, which has the most predictable disease trajectory and comprises the group of patients with the greatest palliative care needs, revealed the same trend with 53.1% of cancer deaths occurring at MDH or GGH and another 26.3% occurring at SAMOC. The data displayed in figure 2 is limited since it only provides the crude number of deaths and their palliative care needs are not known. A greater number of people dying at their own home, care home or at a hospice means that more critical acute hospital

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<sup>2</sup> In this Atlas the need for palliative care for adults was calculated by adapting the conceptual framework for measuring the global burden of serious health-related suffering (SHS) of the Lancet Commission Report on Palliative Care and Pain Relief (Knaul FM et al, 2017). SHS is defined as suffering associated with a need for palliative care. A multiplier for certain conditions deemed to have palliative care needs was applied to the total yearly deaths based on 2014 data.

beds could be freed, however, this would also necessitate well developed community services including 24/7 community care and support with the appropriate professional input.

**Figure 2: Percentage number of deaths in Malta by place of death (2022)**



**(Source & acknowledgement: Malta Mortality Registry)**

\* 'Others' include death outside a health/ social care setting

### 2.3. An overview of palliative care services in Malta

Palliative care services in Malta are provided by both the public health care system and the voluntary sector as described below. Whilst the below-mentioned services and initiatives represent opportunities and strengths in the current system, they are far from enough to meet the needs of all patients who require palliative care. Insufficient human resources is one of the main shortfalls. The EAPC recommends two specialised palliative care services (one home care team and one hospital team) every 100,000 inhabitants (34). According to the EAPC Atlas of Palliative Care in Europe 2019, Malta has 0.4 services per 100,000 inhabitants ranking in the 3<sup>rd</sup> quartile amongst 49 other countries in the WHO European Region, below the average of 0.8 services per 100,000 population (39).

The strengths and weaknesses in the current set up of palliative care services in Malta will be described in more detail under the various sections in Chapter 3, followed by proposed actions on how they will be addressed.

### **Services offered by the public health care system**

Services provided by the public health care system consist mostly of the specialist services offered by the Palliative Care Unit (PCU) for adults and the Rainbow Ward (paediatric oncology ward) for children, at Sir Anthony Mamo Oncology Centre (SAMOC). These services offer care for oncology disease only. The PCU is a 16-bedded ward set up in 2015 and which took over the services previously provided through Sir Paul Boffa Hospital. It caters for adult patients and provides mostly specialist hospital-based in- and out-patient palliative care services using a multidisciplinary team approach (54).

The admission and referral criteria of patients to the PCU include complex symptom control; supportive care for patients no longer receiving active treatment; and care of the dying patient with specialist palliative care needs. According to 2018 hospital activity data, out of 294 episodes of patient discharges from the PCU, 223 (76%) were due to death within the ward. The average length of stay (LOS) of in-patients was 24.5 days and the median LOS was 15 days. Therefore 50% of patients stayed at the PCU for more than 2 weeks and beds were being blocked by patients whose symptoms have been controlled and yet could not be discharged due to insufficient community palliative care support or availability of beds in nursing homes.

A pain management clinic for palliative and oncology patients is also held at SAMOC on a once weekly basis by a consultant anaesthetist specialised in the area. A few paediatric cases are at times also reviewed.

Palliative care services available in Gozo, in both the acute Gozo General Hospital (GGH) and in the community are limited. There are presently no dedicated specialist palliative care beds at GGH. A specialist palliative care outpatient clinic is held three times per month, whilst Hospice Malta offers support to Gozitan patients and their relatives in the community. More needs to be done to strengthen and develop the provision of palliative care on the island of Gozo so that people can benefit from palliative care closer to their home.

In 2022, Active Ageing and Community Care (AACC) launched a pilot project to improve the provision of palliative care in care homes for the elderly run by the Government. A multidisciplinary team of health care professionals was given training in palliative care, and the necessary equipment was provided. The project was initiated at the Mtarfa Home for the elderly and will be gradually extended to other care homes (55).

## **Services offered by the voluntary sector**

### **Hospice Malta**

Hospice Malta is a non-governmental organisation founded in 1989 and is the main provider of community palliative care services to people with cancer and other chronic progressive conditions such as neurological, cardiac, respiratory, renal and liver diseases. Approximately 75% of referrals are for patients with a cancer diagnosis. The organisation is reliant on volunteers as well as professional salaried staff including nurses, social workers and doctors. The organisation is financially supported by the Ministry for Health through a service-provision agreement since 2001 although still reliant on some fund-raising activities.

Hospice Malta offers a wide range of services such as day care, home care, physiotherapy, social work services, transport, spiritual and bereavement support and loan of medical equipment to facilitate care for people at home. It also liaises with specialist staff at the PCU when patients are discharged into the community. There is good collaboration and communication between the multidisciplinary team working with Hospice Malta and those working at the PCU to better support patients' transition from hospital-based to community-based care and vice versa. The demand for various services offered by Hospice Malta including home care services, bereavement services and the demand for the loan of specialised equipment, has increased significantly over the years. This has led to the expansion of services offered and a consequent rise in the number of salaried health care professionals, necessitating greater financial assistance from the Government.

Hospice Malta also plays an important role with respect to education on and promotion of palliative care. Hospice's education unit provides in-service education and training to staff and volunteers to ensure that they have the necessary knowledge and skills, as well as educational sessions at both undergraduate and post graduate levels. A training course in palliative care leading to the award of the European Certificate in Essential Palliative Care (ECEPC) is provided in conjunction with Princess Alice Hospice, UK. Around 200 doctors have undertaken this course, the majority being family doctors.

A new hospice facility (St Michael Hospice) for the provision of palliative care services has been inaugurated in January 2025. The premises were handed over to Hospice Malta by the Church in 2016 and through Government, corporate and EU funds has been refurbished and restructured. will enable Hospice Malta to expand the present community services including day therapy services, as well as introduce a number of out-patient clinics. It will also comprise a 16-bedded in-patient palliative care facility complementing all the other services for a more comprehensive approach. St Michael Hospice will also enhance the organisation's educational wing which will open many opportunities to exchange expertise with other Hospices across Europe and beyond.

### **ALS Malta Foundation**

ALS Malta Foundation is a voluntary organisation that aims to raise awareness and provide support to patients suffering from Amyotrophic Lateral Sclerosis (ALS) and other neurological conditions. This organisation set up Dar Bjorn in 2017, a residential facility with 13 beds for patients with severe neurological conditions. Currently the Foundation has two homes in Qormi and Żebbuġ comprising of a total of 43 beds. Further expansion is on the cards including works on a larger Dar Bjorn Respite underway aiming to extend care to more individuals.

Patients are provided with 24/7 nursing care as well as other services including physiotherapy, occupational therapy, psychological, spiritual and nutritional services. The facilities include the latest medical technology and intelligent smart home systems. Services are offered to patients free of charge whilst the organisation relies on donations as well as financial support from the Government.

### **Other Voluntary Organisations**

Puttinu Cares Foundation is a children's cancer support group, which was officially set up in 2001. It seeks to: advocate on behalf of affected children and their families by representing their needs; promote models of good care and practice; and to support families with a national information service.

The Karl Vella Foundation is a voluntary organisation which was established to provide educational and psychological assistance to children in families disrupted by serious illness of a family member.

## **3. Chapter 3 – The future of palliative care in Malta**

### **3.1. Purpose and scope of the strategy**

The purpose of this strategy is to serve as a roadmap to set the direction and guide change with respect to palliative care in Malta for the 10-year period 2025 – 2035. Change will be enacted through initiatives that address the way society views issues surrounding the provision of palliative care and death; guide investment in and development of the palliative care work force; and inform the development and delivery of palliative care services. Being the first palliative care strategy for Malta, the plan is comprehensive and ambitious, and its implementation can be carried out gradually according to a detailed action plan delineating which initiatives are to be considered for implementation in the short-, medium- and long-term. The strengthening and development of a well-trained palliative care workforce is considered as an important building block on which implementation of the rest of the initiatives will depend.

The strategy abides by the definition of palliative care as provided by WHO (1) and EAPC (2,3), both of which stipulate that palliative care is an approach that improves the quality of life of patients and their families dealing with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain, of other symptoms, and of social, emotional, psychological and spiritual problems. Furthermore, palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death. Therefore euthanasia and physician-assisted suicide are not considered as part of the provision of palliative care (56,57). In accordance with these definitions, euthanasia and physician-assisted suicide are therefore not included as part of the scope of this strategy.

The strategy encompasses in its scope the development and provision of palliative care services to meet the needs of all patients, together with their families and carers, who are dealing with a disease that is known to benefit from palliative care. This includes patients with cancer, and other chronic debilitating diseases such as organ failure, as well as frailty and dementia. Whilst the strategy focuses on adult palliative care services, it also acknowledges the needs of children and young people requiring palliative care, together with their parents and families. Paediatric palliative care is considered different from palliative care for adults suffering from chronic debilitating diseases and facing the end-of-life at a much older age and therefore paediatric palliative care merits consideration through a separate document.

The palliative care approach is applicable across all settings where palliative care can be provided namely: people's own homes, nursing homes and other long-term care facilities, hospital wards and specialist palliative care settings.



The strategy takes an inter-sectoral approach, recognising that in order to provide all-inclusive, integrated palliative care, the health sector needs to work in partnership with all relevant stakeholders; Governmental and non-Governmental, both within and outside the health sector. Finally, working in partnership with people receiving the care, their families and carers is considered essential to truly develop services that meet their needs. Implementation will also require support and action from all key stakeholders within and beyond the health sector, together with continued Governmental investment in and commitment towards palliative care.

### **3.2. Vision and objectives**

**Our vision is to provide access to quality, integrated palliative care to all persons who need it; and to maintain their quality of life, dignity and comfort throughout the course of their illness, irrespective of diagnosis and setting where they are receiving care. Families and carers are to be given the necessary care and support during the illness trajectory and after the loss of their loved one.**

#### **Objectives:**

1. Encourage people to talk more openly about palliative care needs and death and dying as a normal part of life; consider how they would prefer to live and be cared for during their final days; and empower them to engage in conversations about their wishes and preferences with health care professionals, family members and carers.
2. Enhance and develop the palliative care workforce, ensuring adequate numbers of appropriately educated and trained professionals having the necessary skills and knowledge across health services.
3. Strengthen and develop quality, integrated palliative care services at all levels of care, starting from care in specialised palliative care units or hospices, to care at the community level and in the patient's own home.
4. Ensure that patients, their families and carers receive person-centred care and support based on their unique needs and preferences. Services need to be responsive, coordinated and flexible in meeting their changing needs along the course of the illness whilst also ensuring continuity of care across care settings.

**These objectives will be attained through a series of actions under three strategic areas for action:**

1. Raising awareness and understanding on palliative and end-of-life care issues among the general public

2. Organizing and developing quality integrated palliative care services
3. Enabling the delivery of quality integrated palliative care services

### 3.3. Guiding Principles

This strategic policy framework is informed by a set of guiding principles that are considered fundamental to good palliative care.

- **Person-centred care** - People should receive comprehensive care that is respectful of, and responsive to, their needs (physical, emotional, psychological, social, and spiritual needs), preferences and values. Individuals and their families and carers should be included in decision-making about their care and provided with information to make informed choices. The voices of persons in need of palliative care, their families and carers should be heard, considered and valued in the planning and development of palliative care services.
- **Respect for patient's autonomy and dignity** - In palliative care, the autonomy of each person as a unique individual is acknowledged, valued and respected. Efforts should be made to empower patients to make their own decisions as much as possible regarding place of care, treatment options and access to specialist palliative care. However, there will be instances where the decision-making capacity is not available or not wanted by the patient, and decision-making shifts to the family or the palliative care staff. Palliative care should also be delivered in a respectful, open and sensitive way, sensitive to personal, cultural and religious values, beliefs and practices (2).
- **A focus on quality of life** - A central goal of palliative care is to achieve, to support, to preserve and to enhance the best possible quality of life, including good symptom control. Care is guided by the quality of life as defined by the individual (2).
- **Integrated and accessible palliative care** - Integrated care can be briefly described as: the right care, at the right time, in the right place, by the right person (58). To be sustainable and accessible to all persons who need it, palliative care should be integrated into all services and settings of the health-care system including: in people's own homes, long-term care facilities, acute care hospitals and specialised palliative care settings. It is both unsustainable and undesirable that an ever-increasing number of chronically ill and dying patients are cared for primarily in a hospital setting. Countries are therefore urged to prioritise the provision of palliative care services in the community and at home (6).

- **Carers are valued and are provided with the support and information they need** - Carers provide an essential component of palliative care and very often, they provide the majority of care for a person whose life is limited by illness. Unfortunately, carers' needs are often not considered in care planning. Their role should be acknowledged and respected and their health and wellbeing needs to be considered as a component of palliative care needs assessment, including bereavement support.
  
- **Inter-disciplinary and inter-sectoral approach to care** - Whilst the palliative care approach (section 3.5.1.1.) can be put into practice by a single person from a distinct profession or discipline, the complexity of specialist palliative care can only be met by continuous communication and collaboration between the different professions and disciplines in order to provide physical, psychological, social and spiritual support (34). Furthermore, an inter-sectoral approach is essential since to provide comprehensive, integrated palliative care, the health sector needs to work in partnership with all relevant stakeholders; Governmental and non-Governmental, both within and outside the health sector.
  
- **Quality and evidence-based care** - The development of this strategy document itself has been guided by key international recommendations, resolutions and guidelines. Health care providers should be guided by evidence-based practice and locally developed guidelines. Ongoing research, monitoring and evaluation is necessary to define and assess quality standards, as well as management and treatment guidelines.
  
- **Due importance given to the needs of vulnerable groups** – When planning the provision of palliative care services, special consideration needs to be given to the unique needs of certain groups of people who in view of their physical and/or mental state and/or their social circumstances, find it more difficult to access palliative care services, may have difficulty communicating their needs and wishes, and are at greater risk of having their palliative care needs overlooked. These groups include: the frail elderly including those living alone and those living in residential long-term care facilities; persons living with severe mental disorders including those being cared for at mental health licensed facilities; persons with physical and/or intellectual disability; migrants, refugees and asylum seekers; inmates at correctional facilities; and persons living in poverty and those experiencing homelessness.

### **3.4. Raising awareness and understanding on palliative and end-of-life care issues among the general public**

Palliative care was originally developed for patients that have reached the end stage of their life. However, the term has been broadened to encompass chronic, debilitating diseases other than cancer and should start well before a patient reaches the end-of-life. Yet, for many Europeans, the term “palliative care” is still perceived as an announcement that death is imminent. Many people do not understand its meaning or don’t have knowledge of what services are provided under its umbrella (6). Research has revealed that there is a strong stigma attached to palliative care amongst patients and their caregivers (59). Poor public awareness and recognition of the scope of palliative care not only create a barrier to equitable access to such care (6) but have also been identified as a key barrier to the development of palliative care at the European level (60).

Apart from the stigma surrounding palliative care, it is also important to note that the subject of death and dying is rarely openly discussed in modern society and is a source of fear and anxiety for many. The lack of openness and discussion about this sensitive subject frequently has adverse consequences. For instance, families and carers of people who are approaching their end-of-life may be unaware of their wishes and preferences such as on treatment options. It may be distressing for families and carers having to take delicate decisions about the care their loved one receives when they are not entirely sure they are making the choices they would have done themselves.

Little is known about public perceptions of death and dying, and public awareness, knowledge and attitudes towards palliative care in Malta since no large-scale population-based studies have been conducted locally. However, there clearly is a lack of open discussion about these sensitive subjects. Feedback received from the stakeholder consultations emphasised the difficulties experienced by health professionals to start end-of-life conversations with patients and relatives. While this is in part the result of health professionals lacking the knowledge, training and skills to deal with such situations, one cannot underestimate the importance of patients and family members being able to engage in and facilitate such a delicate conversation. The fact that the majority of patients in Malta die in institutions rather than at home is indicative of the need to not only strengthen community palliative care services and make them more accessible, but also to address the fears and anxiety of family members in relation to having a loved one dying at home.

It is deemed crucial for there to be a population-based change in the way people consider their own death and that of their loved ones. In this regard, concerted effort needs to be made by all stakeholders including the public, NGOs, professionals (including those working in the health, social and education sectors) and the media. Public awareness of the purpose and benefits of palliative care should be promoted to increase understanding and counter the negativity that can be associated with it. People need to be aware of what to expect from a

palliative care service and how to access it. Furthermore, whilst having conversations about death and bereavement can be difficult, they are crucial to enabling the delivery of patient-centred palliative care.

### **Recommendations:**

Using an inter-sectoral approach, the following recommendations are being put forward:

- **Develop a public awareness strategy to enhance public awareness and understanding of the concept of palliative care; its purpose, benefits, services available and how services can be accessed.**
- **Promote greater open discussion about death and palliative care to support and encourage people to plan ahead and talk with their loved ones and health professionals regarding their care towards the end-of-life. This will also help to encourage people to offer practical support to those within their community who are nearing the end-of-life.**
- **Explore ways how the education sector could help introduce discussions about death, grief and loss, in order to sensitise people at a young age and empower communities to be supportive.**
- **Explore ways of engaging the public to talk about death and dying utilising a broad communication strategy.**

Education and awareness amongst patients' families and caregivers, and amongst health care professionals are considered in greater detail in sections 3.5.5 and 3.5.1.3 respectively.

## **3.5. Organizing and Developing Quality Integrated Palliative Care Services**

### **3.5.1. Developing the palliative care workforce through education and training**

#### **3.5.1.1. Establishing a graded system for palliative care delivery**

A compassionate, skilled, knowledgeable, and competent workforce is fundamental for the development of good quality, integrated palliative care services. Palliative care delivery

should be structured into three levels of ascending expertise and specialisation (2,4,19). This key approach is necessary for the integration of palliative care into all healthcare services and settings and can be achieved through the provision of adequate education and training along the following 3 levels:

- **Level 1: Palliative Care Approach (basic level)**

The Palliative Care Approach aims to promote both physical and psychosocial wellbeing. It encompasses the use of pharmacological and non-pharmacological measures for symptom control; communication with patients, their family and with other healthcare professionals; and shared decision-making and goal-setting in accordance with the principles of palliative care (4).

This approach should be utilised by all healthcare professionals in any location be it in the hospital or in community settings such as patients' own homes and long-term care institutions. It should be a core skill of every health professional. Indeed, the Council of Europe recommends that all professionals working in healthcare should be confident with basic palliative care principles and able to put them into practice (2,19). This approach enables many patients with palliative care needs to have their needs successfully identified and met without being referred for more specialised care, although staff need to know when to refer or seek expert advice or information.

- **Level 2: General Palliative Care (Intermediate level)**

General Palliative Care can be provided by health care professionals who are not specialists in palliative care, however, treatment of life-threatening diseases may be part of their daily work. They may have undergone some additional training and gained experience in palliative care. Such intermediate level expertise may be available in hospital or community settings. Professionals providing general palliative care need to be able to access advice and support from specialist service providers when required.

Examples of the workforce that may provide this type of care includes but is not limited to:

- Secondary care staff working in all clinical specialities and in general wards
- Primary care staff
- Staff working in care homes
- Community pharmacists
- Chaplains/ Spiritual directors

- **Level 3: Specialist Palliative Care (Advanced level)**

Specialist palliative care services treat patients having more complex and demanding care needs. The provision of specialist care takes a multidisciplinary team approach and members of the team undertake specialist training in the area.

The workforce that may provide this type of care includes: medical doctors specialised in palliative care medicine, palliative care nurses, pharmacists, professionals working in the mental health field, allied health and social work professionals, as well as chaplains/ Spiritual directors.

**Figure 3: The three levels of ascending expertise and specialisation**

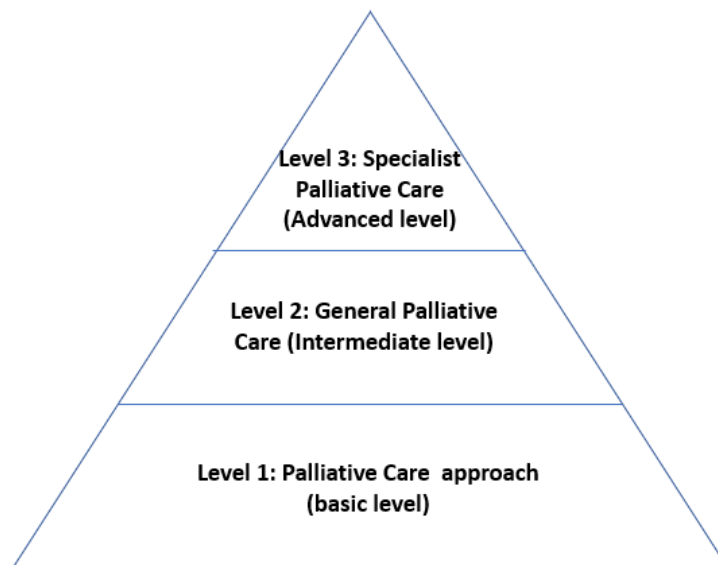


Figure 3 depicts how this graded system of palliative care delivery should be structured. Specialists in palliative care are at the tip of the pyramid, denoting that they comprise the smallest portion of the palliative care workforce. The specialist workforce alone will never be enough to meet all the needs of persons living with serious illness and their families. Most palliative care provision occurs at level 1 (palliative care approach) and level 2 (general palliative care), which is why it's essential that the palliative care knowledge and skills of all health professionals are enhanced.

### **3.5.1.2. Deficiencies in knowledge, skills and attitudes**

Insufficient education, knowledge and training among health care professionals on the role and scope of palliative care is an important barrier to improving access to palliative care services. For instance, healthcare professionals can feel they are failing or letting the patients

down if they refer them to palliative care. Palliative care can help to ensure a better balance between the expectations of disease treatment and improved quality of life. The introduction of palliative care can reduce necessary hospital admissions and this benefits both patients and their families and health care services (15). Continuing to prescribe and conduct only medical treatments with a curative intent that have become futile, sometimes even against the patient's wishes can be challenging for all. The focus on curing patients and on extension of life leads to unnecessary prolongation of the dying process and is detrimental to the quality of life near death. Many are also not aware that palliative care can and should be provided along-side curative treatments. There is also little awareness that palliative care is suitable not only for people with cancer but also for all other chronic progressive diseases. Furthermore, avoidable suffering of treatable symptoms such as pain, may be perpetuated due to prejudice and misinformation about the appropriate medical use of strong opioids (6,61) and other pain relieving medications and techniques.

Deficiencies in communication skills also have a negative impact on the provision of palliative care. Indeed, care outcomes are influenced by the quality of discussion that health care professionals have with patients and relatives (62). Family members and carers who participated in the focus group as part of the consultation process, were particularly critical of the circumstances and manner in which bad news regarding diagnosis and prognosis was given, mostly at Mater Dei Hospital. Without the proper knowledge and training, staff feel unprepared and uncomfortable talking about death and talking to people who are grieving or have been recently bereaved.

A local study also revealed that doctors have difficulty dealing with complex ethical dilemmas arising during end-of-life decision-making. In the absence of a legal framework and official guidance on this sensitive subject, doctors tend to rely on their personal philosophy of life and religious beliefs to guide them in this difficult area of practice (63,64). In order to address the deficiencies in this important area, a set of guidelines have recently been developed (Section 3.6.2.3).

### **3.5.1.3. Addressing the educational and training needs of the workforce**

Education and training needs must be addressed at all three levels of palliative care delivery described in section 3.5.1.1 above. To enable all service providers to use the **palliative care approach** or the basic level, palliative care has to be included in the curricula for medical, nursing and other related professionals' basic undergraduate education (2). This is already the case in Malta; undergraduate curricula for the relevant health care professions already include palliative care, however, the extent to which the topic is covered by the different curricula varies. More needs to be done with respect to the knowledge and skills of staff working in elderly care homes/ long-term care facilities and mental health licensed facilities.



At the **intermediate level (general palliative care)**, the knowledge and skills of health care professionals can be enhanced through Continuing Professional Development (CPD), education and training courses and/or the inclusion of palliative care as part of their postgraduate training. Presently, palliative care features in the Specialist Training Programme in Oncology, Family Medicine, Geriatric Medicine and General Surgery in Malta. With respect to **specialist palliative care**, Malta recently made an important development with the establishment of the Postgraduate Specialist Training Programme in Palliative Medicine. Furthermore, the Department of Nursing, Faculty of Health Sciences at the University of Malta in 2022 set up the first postgraduate Master of Science in Nursing (Palliative Care), for graduate nurses who choose to specialise in palliative care.

Hospice Malta contributed greatly to the advancement of professional development in palliative care in Malta. This NGO provides in-house education and training courses to all its employees as well as facilitates the provision of an annual course leading to the award of the European Certificate in Essential Palliative Care (ECEPC). Doctors enrolled in the Specialist Training Programme in Family Medicine currently have the opportunity to undergo a training rotation with Hospice Malta's community team. This training opportunity could be extended further to Basic Specialist Trainees (BSTs) from relevant specialties and GP trainees through regular fixed term rotations within St Michael Hospice once this is opened.

#### **3.5.1.4. Defining the necessary skills and competence**

There are **three areas that are considered as essential for workforce development in palliative care**. These are:

1. Communication
2. Assessment of needs and preferences
3. Symptom assessment and management (pain, nausea & vomiting, agitation, anorexia/cachexia syndrome (ACS), fatigue, and breathlessness (35,37))

The palliative care workforce is vast, spanning across various settings in the community and in hospital, and comprising various professionals and staff groups. The whole workforce should have good knowledge of the basic palliative care principles and be able to put them into practice. However, the level of skill and competence required in each of the above-mentioned areas will vary according to the level of care being provided (basic, intermediate, or advanced) and according to the role that each profession plays in the provision of palliative care.

Good communication is one of the most important aspects of providing good quality care. Health care professionals need to have good communication skills to be able to connect with patients, understand their needs and wishes, and support them to make informed decisions

about their care. They also need the skills to address the specific communication needs of persons whose ability to understand speech and written information and/or their ability to express their thoughts through speaking or writing is affected by an illness such as: neurological diseases, stroke or cancer, disability such as deafness or blindness and intellectual disability.

All relevant stakeholders including specialist palliative care services, educational institutions, professional bodies, NGOs such as Hospice Malta, the Church and representatives of ethnic minority groups need to work together to define the skills and competence necessary at each level of care and for each type of profession, and to develop an adequate education, training and re-training framework.

### **Recommendations:**

- **Encourage collaboration between all relevant stakeholders to:**
  - **Establish a Palliative Care Competence Framework delineating the level of knowledge and competence necessary at each level of care and by each professional group depending on their role in the provision of palliative care. Due consideration needs to be given to the following areas: communication; assessment of needs and symptom assessment and management.**
  - **Design effective education and training programmes that meet identified workforce needs, including opportunities for training abroad.**
  - **Promote a culture of continuous professional development.**
  
- **Review the undergraduate curricula on palliative care knowledge and skills of all relevant professions and where necessary enhance them proportionate to the role that each profession plays in the provision of palliative care.**
  
- **Review the relevant medical specialist training programmes with a view to introducing or enhancing their palliative care component where and as necessary. Certain specialties would benefit from the inclusion of rotations working with the specialist palliative care team.**
  
- **Enhance the post-graduate educational and training opportunities for doctors, nurses and allied health professionals.**
  
- **Undertake a needs assessment with respect to the education and training needs of professionals already practicing in different settings including primary care, long-term care, and hospitals with a view to enhance their skills as required through CPD and other education and training opportunities.**

- **Promote and support existing educational and training initiatives such as those organised by the Hospice Malta.**
- **Prioritize the development of the specialist care workforce since they are a key resource for the provision of formal and informal education to non-specialist staff.**
- **Ensure that cultural sensitivity is given due consideration in the education and training provided to meet the needs of our culturally diverse population. The availability of interpreters is considered essential to overcome language barriers.**
- **Provide opportunities for education and training in the provision of spiritual care to address the spiritual needs of all people receiving palliative care irrespective of whether or not they believe in a particular religion or faith.**
- **Provide opportunities for health care professionals to further their knowledge and understanding of ethical guidelines surrounding end-of-life decisions.**

### **3.5.2. Developing Specialist Palliative Care Services**

Specialist palliative care is a holistic approach to care that includes the provision of medical and therapeutic interventions as well as psychological, social, and spiritual support to patients having palliative needs and nearing the end-of-life. Support is extended to their families and carers. The complexity of care necessitates a broad range of skills and therefore can only be delivered using a collaborative, multidisciplinary team approach.

#### **Specialist palliative care can be provided in the following ways:**

- I. In inpatient specialist palliative care units and inpatient hospices
- II. In the hospital setting where multi-disciplinary palliative care teams work with patients and other hospital-based staff in wards and clinics
- III. In the community setting through:
  - Community teams which provide specialist advice and work alongside general practitioners/family doctors and other health professionals, enabling specialist care to be provided in the patient's home or care home;
  - Day care services, which enable patients to continue living at home while having access to day facilities run by a multi-disciplinary health and social care team

The different modalities in which specialist palliative care services can be provided are described below. The below proposals for the organisation and development of palliative care services are highly dependent on the adequate injection of appropriately trained and

supported human resources (sections 3.5.1 and 3.5.3). Palliative care services need to be planned out and strategically developed gradually over the next 5 to 10 years in synergy with the development of the palliative care workforce since appropriate staffing levels are integral to the effective delivery of care.

### **3.5.2.1. The Specialist Palliative Care Unit (PCU) or Inpatient Hospice**

These provide specialist inpatient care. It is usually a ward or unit with a capacity of 8 to 15 beds that is located within a hospital complex, although it may also exist as a stand-alone service. Its main functions are to:

- Provide crisis intervention for patients with complex symptoms and problems, to stabilise the patient and provide the necessary psychological and social support. The patient is discharged or transferred to own home or to another care setting when stabilisation is achieved.
- Provide inpatient care for patients in their last phase of life when treatment in an acute hospital is not necessary and care at home or in a nursing home is not possible or ideal.

A distinction is sometimes made between a PCU and an Inpatient Hospice, with the latter being mostly used for end-of-life care and is usually of a stand-alone type. However, their functions often overlap. The environment in an Inpatient Hospice should be homelike, having quiet and private areas and facilities for social activities, such as kitchens or living rooms (34).

Malta presently has a 16-bedded PCU located within SAMOC, while work is underway to set up St Michael Hospice; a community based 16-bedded unit run by Hospice Malta. In addition, Dar Bjorn offers inpatient hospitality and care for 43 persons with progressive degenerative neurological diseases, while work on Dar Bjorn Respite in Żebbuġ is underway with the aim to extend respite care to more individuals in an impactful environment (Section 2.3).

Any future plans to gradually increase the number of specialist palliative care beds available should take into consideration international guidelines, local needs assessments and the palliative care workforce plan. It is essential that any increase in bed numbers happens in tandem with the adequate injection of appropriately trained human resources.

### **3.5.2.2. Specialist Palliative Care Services in the acute general hospital**

Patients having palliative care needs will undoubtedly make use of the acute hospital services at some point, predominantly in their last year of life. One of the main challenges that Malta faces is the dependence palliative care has on acute hospital settings with the majority of

deaths from diseases having palliative care needs occurring at MDH and GGH (section 2.2.1). Furthermore, hospital activity analysis data<sup>3</sup> revealed that 25% (401) of all patients who died at Mater Dei Hospital in 2016 (1605) had 5 or more admissions in their last year of life, of which 48% (192) were cancer patients. The demand for palliative care is high and this is mostly and limitedly provided by staff without specific expertise in the area. The availability of and accessibility to specialist services in the acute general hospital is therefore considered crucial to enhance the quality of care provided to patients, their families and carers and to support staff working in acute general hospital wards.

### **A. Hospital Palliative Care Support Team**

The Hospital Palliative Care Support Team provides specialist advice and support to staff working within the acute hospital environment. The team is mobile so that care may be provided directly on the acute hospital wards.

Support may be provided on pain assessment and management and control of other symptoms, as well as psychosocial support to patients, their relatives and carers. The team provides advice on palliative care and has a mentoring role and may offer formal and informal education to clinicians and other staff. The specialist palliative care team is an advisory service and is not meant to take over the care of the patient but work alongside other hospital teams and complement their work.

An important role of the team is the provision of seamless palliative care, including facilitating the discharge of patients from the acute hospital setting and their transfer to other appropriate settings based on their individual needs and preferences. For instance, patients may be deemed in need of specialist care in a PCU or a hospice unit or else they may be considered fit to be transferred to a community setting, such as a nursing home or their own home with adequate support. The team needs to co-operate and liaise closely with other services outside the general hospital setting (34).

Once an adequate complement of suitably educated and experienced palliative care professionals in the acute hospital setting is established, greater support can be given across the acute setting. This would enable the integration of palliative care in the care plans of a greater number of patients, especially non-oncology patients. When feasible and indicated, cooperation between palliative care professionals and other health care professionals could be facilitated through for example: multidisciplinary team meetings held on certain wards such as the Medical Assessment Unit (MAU) or with certain medical and surgical specialties.

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<sup>3</sup> Source: Hospital Activity Analysis database

## **Recommendations:**

- **Develop consultant-led hospital palliative care support teams having access to other key professionals that are not part of the team when and as necessary.**
- **Ensure there are protocols in place delineating the roles and responsibilities of hospital palliative care support teams and how they should operate in the acute hospital setting, including the referral criteria.**

### **B. Palliative outpatient clinic**

Presently, palliative outpatient clinics are held regularly for people living in the community and who are physically able to attend the clinic. The service is affiliated to the PCU located in SAMOC. Since the start of the Covid-19 pandemic, many patients started being offered this service via tele-consultation. An outpatient session is also held three times per month in Gozo. Assessment of the needs of Gozo in this regard is essential. Outpatient services are considered to be an important component of community palliative care (34) and can be further strengthened as the palliative care workforce is enhanced.

#### **3.5.2.3. Community Palliative Care**

Community Palliative Care is provided in patients' own homes, in nursing homes and in long-term care facilities, including mental health licensed facilities. Hospice Malta is presently the main provider of community palliative care. Strengthening community palliative care services is crucial to enable more patients to stay in the community for as long as possible, and to die at home or in another community setting if it is the patients' and their relatives' wish for them to do so.

In line with the principles of the graded system of palliative care delivery (Section 3.5.1.1), not all patients with advanced disease require the input of specialist palliative care professionals. Most palliative needs in the community setting can be met by general practitioners, nurses and medical staff at the primary care level. These professionals need to have a good grasp of the palliative care approach or have had some additional training in palliative care and are therefore able to provide intermediate level palliative care. However, there are instances where staff need the advice and support of specialists in palliative care. This support needs to be readily available when and where required and provided on a 24/7 basis as necessary.

## **A. Home palliative care teams**

Home palliative care teams or community teams provide specialist advice and support to other professionals such as general practitioners or family doctors, nurses and other medical staff who are caring for patients with palliative care needs, together with their families and carers, in their own homes, nursing homes or in long-term care settings. Similar to hospital palliative care teams, home palliative care teams have an advisory and mentoring function by providing their expertise in pain management, symptom control and psychosocial support. In instances where the level of involvement of non-specialist staff is low or in cases of highly complex symptoms and problems, the home palliative care team may provide more direct “hands-on” care to the patient. The team also plays a role in facilitating the transfer of patients between hospital and home (34).

### **Recommendations:**

- **Strengthen current community-based palliative care services whilst working in collaboration with NGOs especially Hospice Malta.**
- **Develop consultant-led home palliative care teams to provide advice and support professionals not specialised in palliative care who work in the community.**
- **Develop protocols delineating the roles and responsibilities of the home palliative care team, referral criteria and how care should be coordinated between hospital and community care.**

## **B. Out-of-hours specialist palliative care services**

Access to specialist palliative care advice outside office hours is important to health care professionals working in the community. Specialist home care teams should ideally be accessible for advice seven days a week and 24 hours a day.

A 24-hour crisis intervention service is being provided by Hospice Malta through a subcontracted service, although the service needs to be strengthened and expanded further. It is imperative that Government and Hospice Malta continue to work in synergy to strengthen current community services, not to duplicate services and ensure coordination between services.

### **Recommendation:**

- **Make arrangements for health care professionals not specialised in palliative care and working in the community to have adequate out-of-hours access to specialist services for advice. It is acknowledged that staff shortages may limit the availability of an out-of-hours service.**

### **C. Day-care services**

Day hospices or day-care centres can be spaces in hospitals, hospices, PCUs or the community especially designed to promote recreational and therapeutic activities among palliative care patients. Day care services focus on creative living and social care, offering patients opportunities to participate in various activities during the daytime outside their familiar surroundings, to offset social isolation as well as to provide respite and relieve the burden of care on relatives and carers. The range of day care activities provided includes nursing procedures, personal care, physiotherapy, occupational therapy, complementary therapies, relaxation, music and art therapy. Medical consultations are not usually part of day care activities although there may be day-care centres that offer some treatments, such as a blood transfusion or systemic anti-cancer therapy, while at the centre (34).

At present, in Malta patients have access to one Day Therapy Unit which is open three days per week, although this service has been impacted by the Covid-19 pandemic. Systemic anti-cancer therapy (SACT) and radiotherapy are not provided at this centre. The service is run by Hospice Malta and is located in the recently inaugurated St Michael Hospice Centre in St Venera. This centre includes a new Day Therapy Unit which will be offering better services in a modern environment as well as new administrative centre for Hospice.

#### **Recommendation:**

- **Strengthen and expand current day-care services to give more opportunities to patients to receive care in the community setting whilst also supporting their relatives and carers.**

### **D. The role of the family doctor**

Family doctors or general practitioners, in both the public and private sectors, play a pivotal role in the delivery of community palliative care. Family doctors are best positioned to identify palliative care needs earlier on in the disease trajectory (section 3.6.2.1) and to apply the biopsychosocial approach to care. This is especially true in the private sector where persons or families have a designated family doctor who, after years of caring for the person/family, has established a strong doctor-patient relationship built on trust. This may in turn facilitate difficult palliative and end-of-life care conversations, and given the right support, the family doctor may enable persons to spend their last few days of life in their own home if it is their wish to do so.

This strategy acknowledges the fact that community palliative care services can be truly strengthened if family doctors are supported to the highest degree possible. They should be empowered by: giving them all possible opportunities for education and training (section 3.5.1); providing them with specialist support through community palliative care teams



including out-of-hours support (Section 3.5.2.3); strengthening and improving communication channels between family doctors and other health care professionals involved in the care of the patient at the primary, secondary and tertiary levels (Section 3.6.3); having timely access to medicines in the community (Section 3.6.5); and timely access to patients' hospital medical records (Section 3.6.6).

### **3.5.3. Planning and sustaining the palliative care workforce**

Section 3.5.1 addresses the development of the palliative care workforce in terms of education and training needs, while section 3.5.2 delineates how the specialist palliative care services should be structured. An important aspect that needs to be addressed is the availability of appropriately trained workforce. Substantial planning and investment in human resources is an essential prerequisite for the development and expansion of palliative care services.

#### **3.5.3.1. Staff requirements**

A fundamental principle of palliative care is that no one individual or discipline possesses the full range of skills necessary to comprehensively address the varied needs (physical, psychological, social and spiritual) of patients and their families. While the palliative care approach can be put into practice by a single person from a distinct profession or discipline, the complexity of specialist palliative care can only be met by a multidisciplinary team approach. This applies for the various modalities in which specialist palliative care can be delivered including palliative care units/hospices, Hospital Palliative Care Support Teams and Home Palliative Care Teams.

In general, the multidisciplinary team should be consultant-led and should consist of a core team comprising nurses and doctors who have undergone specialist training in palliative care. The core team should have access to other key professionals including: social workers, physiotherapists, occupational therapists, pharmacists, mental health professionals, dieticians, speech and language therapists and spiritual directors/ chaplains. They must also have effective support of administration and support staff (34)

International guidelines by EAPC (3,34) and the Irish NACPC (4) about the quantity and composition of the multidisciplinary team in the various settings of palliative care delivery should be used to guide the development of a workforce plan for Malta for the next 5 to 10 years. Such guidelines must be adapted to the local context, taking into consideration local

challenges and needs. The plan also needs to be responsive to the changing population demographics, needs and demands.

### **3.5.3.2. Workforce shortages**

It is acknowledged that currently there are major gaps in the palliative care workforce in terms of both quantity and quality of professionals, at all levels of care. For instance, at present, there is only one medical consultant in palliative care, based at SAMOC. In the community setting, the provision of care is led by general practitioners who have undergone training in palliative care, however, together they constitute less than one full time equivalent (FTE). There are also shortages in the availability of other essential members of the multidisciplinary team. For example, certain professional groups that are key to the provision of palliative care such as nurses and social workers, are in short supply.

The short supply of nursing staff in Malta is presently a challenge for the entire health care system and the available nurses tend to be deployed in the various health departments according to a prioritization exercise. In the face of various other pressing health care needs, palliative care tends to be deprioritized, however it is being recommended that palliative care merits to be given greater prominence in terms of financial and human resource allocation.

### **3.5.3.3. Support and resilience**

Delivering care at the end-of-life and supporting people facing loss and grief is difficult and emotionally demanding. Staff can only provide compassionate care when they feel they are themselves also being supported and cared for. This enables them to sustain their compassion, remain resilient, and apply their professional values at all times (65). The environments where these professionals work must be conducive to psychological safety, support and resilience. In view of these difficulties and high risk of burnout, greater support is needed to attract and recruit more professionals and retain the expertise in the field.

Addressing staff shortages is one way of preventing burnout in existing staff. There also needs to be adequate structures and support systems in place that address both the professional and mental health needs of the individuals providing palliative and end-of-life care. Spiritual help should also be available for staff if required. Staff members need to be aware of the skills and techniques for effective self-care, recognition of burnout and compassion fatigue. There must also be adequate support services in place that are readily accessible. All staff in all health care settings who are looking after patients nearing death must be well supported and provided with adequate education and training in those aspects of end-of-life care that are

appropriate to their role. The provision of clinical ethics support is also deemed essential (section 3.6.2.3).

Recruiting and retaining healthcare professionals to work in palliative care can be enhanced by providing career pathways for all disciplines, clear role definitions and opportunities for training, education and research. For instance, the recently developed Training Programme in Palliative Care Medicine for doctors is a step in the right direction as it seeks to build the expertise and address the present shortage of palliative care medical professionals who have a key leadership role in the multidisciplinary team. Having a training programme in place will serve to make palliative care more attractive as a career choice for junior doctors or doctors seeking a change in career path. As to other health care professionals, these also need to be given adequate training opportunities and supported in pursuing a career path in palliative care.

### **Recommendations**

- **Develop a workforce plan for the next 10 years stipulating the quantity and composition of the specialist hospital palliative care support teams, community teams and staff working in palliative care units/hospices. This should be guided by international guidelines on staffing levels required which should be adapted to the local context taking into consideration the local challenges and needs. The plan also needs to be responsive to the changing population needs and demands.**
- **Prioritise action to address the acute shortage of palliative care medical professionals since they have a key leadership role in the multidisciplinary team and in the provision of training and education to other health care professionals.**
- **Develop a plan to attract, recruit and retain more professionals in the palliative care field. This should include measures to provide adequate opportunities for education and training, well-defined career pathways and ensure appropriate working environments that are supportive and prevent burnout.**
- **Ensure there are adequate structures and support systems in place that address both the professional and mental health needs of all individuals in all health care settings who are providing palliative and end-of-life care. Spiritual help should also be available for staff if required.**
- **Ensure that staff members know the skills and techniques for effective self-care, recognition of burnout and compassion fatigue, and are aware of support services they can resort to in case of need.**

### 3.5.4. The role of volunteers

Volunteers are considered as an integral part of the specialist palliative care services, whether they are assisting patients and families directly, or providing other essential support such as raising money. Whilst they cannot take the place of professional staff, they work alongside them in a complementary way. They bring a range of skills, talent, experience and expertise, and can provide services such as: administration duties, assisting at day care centres, providing transport and offering home visits. They can be a source of support and companionship for patients, their families and carers. Volunteers need to be carefully selected, trained and supervised, and they need to act within a team. This should be done under the responsibility of a volunteer coordinator (2,4). Currently, there are around 200 volunteers dedicating their time to Hospice Malta, as well as numerous other volunteers dedicating their time with other voluntary organisations.

#### **Recommendation:**

- **Enhance efforts to recruit and train more volunteers to help support patients, their families and carers**

### 3.5.5. Support for patients, their families and informal caregivers

The unique and essential contribution made by families and informal carers; spouses, partners, relatives and friends, in the provision of care to their loved ones living with serious chronic illnesses and nearing the end-of-life must be duly acknowledged. Their role is crucial and irreplaceable and complements the care provided by salaried palliative care professionals. Due consideration must be given to the needs of families and informal caregivers whose lives are greatly impacted at multiple levels; personal, social, financial, their work and family life, as a consequence of their involvement in the care of their loved one.

Support for families and informal caregivers with the aim of improving their quality of life and well-being, as well as ensuring they can care for their loved ones, is a central component of palliative care provision. Caregivers may need support with the organisation of care and with the actual provision of care (including development of skills to provide physical care and administer medication for their family member). It is also important that they have support to deal with the emotional burden caused by the illness, and will also require bereavement support (6). They also need to be protected from financial losses and job losses as a result of their caring role.

It is also pertinent to acknowledge that in some instances, informal caregivers may be suffering from severe physical and/or mental disorder themselves. Alternatively, the patient requiring palliative care may have been the main informal carer of a family member with

severe physical and/or mental disorder or other dependent vulnerability. Children and/or adolescents whose primary care giver or other family member is receiving palliative care may also need specific attention and support. Such circumstances need to be flagged as early as possible so that the appropriate care and support can be provided in a timely manner.

### **3.5.5.1. Empowering informal caregivers**

Informal caregivers can be empowered to take on a more active role in the care of their loved one by increasing their understanding of the purpose and benefits of palliative care as well as their awareness of the available services and resources they can turn to for support. Section 3.4 has already specified the need to enhance public awareness and understanding of palliative care to counteract the negativity that can be associated with it.

Informal caregivers can be further empowered if they feel confident and competent in taking on the care giving role and the responsibilities associated with it. They must be given the choice to become involved in the care of their loved one at a level which they feel comfortable with, and they must be educated accordingly. Appropriate communication and flow of information to carers from health care professionals about treatment options as well as clear and honest information about the patient's prognosis (with due consideration given to the patient's wishes), is crucial to enable carers to prepare themselves and cope with this information. The psychological, emotional and spiritual needs of caregivers must be given their due importance at all times (6). Family training sessions are currently being provided and booklets for informal care givers are also available. Finally mechanisms should be in place to ensure adequate involvement of service users including patients, families and informal carers in planning, developing and evaluating palliative care policies and services (6,66). Their views, experiences and difficulties in accessing services need to be heard and taken into consideration to ensure that services are continuously evolving, improving and responsive to their needs.

#### **Enabling informal caregivers to care for patients at home for as long as possible**

While no studies on preferred place of death are available for Malta, international studies (51–53) show that many patients would choose to be cared for at home and also to die at home if they are given adequate support in the home environment. Inadequate support for carers in the community has been identified as the major reason why patients are admitted to hospitals, nursing homes or specialist palliative care units. Caregivers may find difficulties due to fatigue, lack of information, improper care coordination across settings and lack of out-of-hours support. Issues with respect to access to medicines and equipment may also

impede patients from being treated in the community and can be a cause of delayed discharges from hospital. Furthermore, the provision of out-of-hours advice and support is important for caregivers taking care of patients at home as well as for non-specialist staff working in the community (4).

In addition to the recommendations made below, a number of initiatives that are described elsewhere in the strategy can contribute to enabling informal caregivers to care for patients at home for as long as possible. These include:

- Out-of-hours care and support, with back-up from appropriate specialists (section 3.5.2.3)
- Assigning a key worker to every patient (section 3.6.3.1)
- Enhancing timely access to medicines and equipment upon discharge from hospital, including having timely home modifications where and as necessary (section 3.6.5)

All efforts should be made to enhance community support to enable patients to be cared for at home for as long as possible. However, it is also being acknowledged that there will be instances where patients who wished to die at home, change their mind as their health deteriorates, and instances where patients develop symptoms which become unmanageable at home. Therefore, there needs to be appropriate palliative care services at all levels of care to meet the wide-ranging needs of patients.

#### **Recommendations:**

- **Enhance support for informal caregivers to become involved in the care of their loved one at a level which they feel comfortable with and provide them with appropriate education accordingly.**
- **Strengthen and enhance the current practice of carrying out a comprehensive assessment of families' and carers' needs as part of the overall needs assessment of the patient, and provide the required support including psychological, spiritual as well as bereavement support. Case managers (section 3.6.3.1) have an important role to play in this respect.**
- **Look out for and address the specific needs of informal caregivers who may be suffering from severe physical and/or mental disorder themselves; family members with severe physical and/or mental disorder or other dependent vulnerability whose main informal caregiver is receiving palliative care; and children and/or adolescents whose primary care giver or other family member is receiving palliative care.**
- **Strengthen collaboration with NGOs responsible for the provision of support, including respite to families and carers.**

- **Enhance respite services for informal caregivers.**
- **Enable adequate service user involvement including patients, families and informal caregivers, when planning, developing and evaluating policies and services. Their views, experiences and difficulties in accessing services need to be heard and taken into consideration.**

### **3.5.5.2. Social support benefits**

Patients, their families and informal caregivers need to be protected from financial losses as a result of their illness and caring roles. To this end, current provisions need to be reviewed and discussions need to be undertaken with all relevant stakeholders on ways how patients with life-limiting illnesses, patients at end-of-life and informal carers could be better supported in terms of benefits and employment issues such as leave for carers.

#### **Recommendation:**

**Undertake discussions with all relevant stakeholders with a view to revise, update and enhance the social support and protection benefits for patients with life-limiting illnesses, patients at end-of-life and informal carers.**

### **3.5.5.3. Bereavement services**

Bereavement services are recognised as a core component of palliative care service provision. Grief and bereavement risk assessment and support should begin early in the disease trajectory of a life-threatening illness and extend till after the death of the patient (34). It should be available in all settings where specialist palliative care is offered including: specialist palliative care units, general hospitals, and community settings (4).

Bereavement care is not the responsibility of a single provider or service; it comprises informal support in families, in schools, at work and in social organisations, as well as in both generalist and specialist health care services (36). According to the public health model of bereavement support, there are three levels (low, moderate, and high) of bereavement risk and need for support. Recent research revealed that nearly 60% of bereaved people are low risk and can deal with grief and bereavement with support from family and friends. They may also require information about grief and available services. At moderate risk level, 35.2% would need additional support from the wider community such as through peer support or volunteer-led groups, whilst the high risk group (6.4%) may need support from mental health services (67).

All health care staff in primary, secondary and tertiary settings should have some level of competence in the delivery of bereavement care (68). Volunteers may be trained to provide group support to families and carers. This may include emotional support, information about grief, and help with managing the various life changes triggered by loss. It is also important for there to be a member of staff fulfilling the role of bereavement service coordinator whose responsibilities would include the selection, training, supervision and assignment of volunteers involved in bereavement support (4).

Bereavement services should particularly take into consideration the needs of children and adolescents, whose way of understanding, expressing and coping with grief may be considerably different to that of adults (4). Special consideration should also be given to cases of complicated bereavement.

#### **Recommendations:**

- **Strengthen and expand current bereavement support services taking into consideration the three levels (low, moderate and high) of bereavement risk and need for support.**
- **Identify a bereavement service coordinator**
- **Provide adequate educational and training opportunities for staff involved in bereavement risk assessment and support.**
- **Provide grief and bereavement risk assessment on an ongoing basis throughout the course of the illness. This should be developmentally appropriate for the patient and family and can be used as a guide to the level of bereavement care that would mostly suit their needs.**

### **3.5.6. Palliative care for children and young people**

Palliative care for children and young people should take an all-inclusive approach to care, embracing the physical, emotional, social and spiritual aspects, starting from diagnosis, and continuing throughout the course of the illness and until death. It focuses on enhancing the quality of life for the child or young person and providing support for the family, extending to



bereavement care. Children or young people in need of palliative care may suffer from life-limiting<sup>4</sup> or life-threatening conditions<sup>5</sup> that can be grouped in four categories:

- **Group 1:** Life threatening conditions for which curative treatment may be feasible but can fail e.g. cancer, irreversible organ failure.
- **Group 2:** Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but where premature death may still occur for example in cases of cystic fibrosis and muscular dystrophy.
- **Group 3:** Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years e.g. Batten's disease, mucopolysaccharidosis and other severe metabolic disorders.
- **Group 4:** Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care e.g. severe brain or spinal injury, severe cerebral palsy (69,70).

Whilst paediatric palliative care shares many common elements with adult palliative care, it is distinct from it (70). Children are not simply 'little adults' and health professionals skilled in adult palliative care, generally lack the expertise to deal with the unique needs of children (71). Indeed, as a speciality, palliative care for children has evolved from paediatrics rather than through palliative care. This is in line with the provisions of the United Nations Convention on the Rights of the Child to the effect that children are best cared for by those specifically trained and experienced in the care of children (6). Children's palliative care has only recently become recognised as a specialty and few specialist Paediatric Palliative Care services exist in Europe (39).

### **Unique considerations and challenges**

Caring for children and young people with life-limiting or life-threatening conditions carries with it certain unique considerations and challenges which make paediatric palliative care different from adult palliative care. These include:

- Most children requiring palliative care have non-cancer conditions and are born with conditions that are often coupled with chronic and complex disabilities.

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<sup>4</sup> life-limiting illness is defined as a condition where premature death is usual as in Duchenne muscular dystrophy

<sup>5</sup> life-threatening illness is where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood. For example: children receiving cancer treatment or admitted to intensive care after an acute injury.

- A small number of children die when compared to adults and the timescales involved in the provision of palliative care can be much longer than for adults.
- Conditions can be extremely rare with diagnoses specific to childhood or young adulthood.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.
- Childhood is characterised by ongoing physiological, emotional and cognitive development. Therefore, paediatric palliative care providers need to understand and be responsive to the child's physiological development when it comes to treatment, as well as the child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Due consideration needs to be given to education, and opportunities to engage in play and childhood activities (70).
- In adolescence, development continues in physical, emotional, social and cognitive spheres, leading to a desire to attain independence. However, the presence of a life-threatening or life-limiting illness tends to cause isolation and dependency. This creates a unique set of challenges that are different from those of children and adults (72).

In Malta, the provision of paediatric palliative care is largely hospital-based while home-based palliative care for children and young people is especially lacking. While there are a few health professionals who provide support at home to such patients, a more formal set-up is required for the provision of such services. In addition, more health professionals working in paediatrics need to be trained so that palliative care can truly be integrated in paediatric care and provided through a multi-disciplinary team approach.

**The main focus of the strategy is on adult palliative care. While many of the principles and recommendations made can be applied to paediatric palliative care, the uniqueness of the speciality merits more detailed consideration in a separate document. Therefore, while this strategy recognises the specific palliative care needs of children, adolescents and their families, taking into consideration their distinctive characteristics and challenges, it paves the way for a more detailed needs assessment, followed by an action plan targeting solely this special section of the population.**

### 3.5.7. Transitional care for young people

Transitional care is “the purposeful, planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions from a child-centred to an adult-orientated health care system”(73).

The period between childhood and becoming a fully independent adult can be challenging and the presence of a life-limiting or life-threatening illness makes it even more complex. The needs of young people at this time are very different from those of children and adults, and special consideration needs to be given as to how they could be addressed. Furthermore, improvements in medical care for conditions which manifest in childhood means that there is a growing number of persons surviving into the transitional years and beyond (72).

It's important that planning for transition starts early, from age 14 at the latest. Care provision needs to be personalised, encompassing the full range of a young person's needs: health, social care, education, meaningful occupation and independent living, whilst also acknowledging the support and emotional needs of their families (74).

**Recommendation:**

- **Strengthen and further develop comprehensive transitional care services for young people, their families and carers. For instance, structured joint and multi-disciplinary transition clinics in palliative care could be set up where the care pathway and forward care plans are formally handed over. The input of the patients and their family and carers are vital and they should be invited to attend and actively participate.**

### **3.5.8. Rehabilitation in palliative care**

A focus on rehabilitation helps to achieve the overarching aim of palliative care which is to attain the best quality of life for patients, their families and carers. The concept of rehabilitation in palliative care applies for both malignant and non-malignant conditions. It entails an interdisciplinary approach through which all those providing palliative care, work collaboratively with patients, their families and carers to enable them to achieve their personal goals. Rehabilitative palliative care seeks to maximise patients' functioning and wellbeing to enhance their independence and social participation, within the constraints of their advancing illness. This approach helps people to adapt to their new state of being as their illness progresses and their health deteriorates (36,75). With the advances in medical treatments, people with cancer and other chronic debilitating diseases are living longer such that the concept of rehabilitation is becoming ever more relevant and important.

**Recommendation:**

- **Incorporate rehabilitation as part of the approach and culture of care at all levels (section 3.5.1.1) of palliative care delivery. This will necessitate training and enhancement of skills amongst the palliative care workforce.**

### 3.5.9. Perinatal palliative care

The perinatal period is a very special one for many pregnant women and their families but can also be extremely difficult in certain unfortunate circumstances when loss of life is experienced at any point during the pregnancy; or the baby is diagnosed with a life-limiting or life-threatening condition and is therefore deemed to be at high risk of dying before or shortly after birth. In such instances, women and their families need all the support they can get to cope with or prepare for the loss of a precious child; to plan and cope with the remainder of the pregnancy and the time around delivery; and to cope with grief in the days, months and years that follow.

According to the newly revised EAPC guidelines (3), perinatal palliative care is general care designed not only to minimise pain in neonates but also to make them more comfortable, promote individualised developmental care and facilitate bonding. Perinatal palliative care should start early, from diagnosis and focuses not only on the needs of the foetus but also on the psychological, spiritual and social needs of the mother and the whole family.

At MDH, a specialised bereavement and support service led by midwives is provided to women who experience early pregnancy loss, or a foetal or infant death. However, these women may also receive care from multiple health care professionals in various health care settings, including community settings such as: public or private GP clinics, public or private prenatal clinics, maternity wards, A&E, and NPICU. For instance, the assessment conducted at a routine prenatal visit may reveal an unexpected loss when the foetal heartbeat cannot be heard or visualized and the health care professional needs to be trained in how to deal with such a delicate situation. It is therefore imperative that health care professionals have the necessary knowledge and skills to provide bereavement support for the family and palliative symptom management to the infant born with a life-limiting condition irrespective of where in the healthcare system the contact is made (76). Emotional as well as spiritual and clinical ethics support if required should also be readily available for those providing care in such sensitive circumstances.

#### **Recommendations:**

- **Conduct a needs assessment with respect to perinatal palliative care services with a view to strengthen and enhance current services as necessary.**
- **Develop clinical guidelines and protocols on the provision of perinatal palliative care.**
- **Provide education and training opportunities for health care professionals to enhance their knowledge and skills in providing perinatal palliative care proportionate to the**

**role that each professional plays in the provision of such care. Consideration should also be given to the provision of basic training to ancillary staff such as clerks and receptionists to ensure considerate encounters with parents and family members going through perinatal loss.**

- **Ensure that emotional as well as spiritual and clinical ethics support if required are readily available for those providing care in such sensitive circumstances.**

## **3.6. Enabling the delivery of quality integrated palliative care services**

### **3.6.1. Governance and financing**

Good governance, leadership and adequate funding are key to the successful implementation of any health care reform. This palliative care strategy, the first for Malta, represents the overarching framework which will guide the development of palliative care services and investment in the palliative care sector within the next decade. There is dire need for a unifying body that brings together all stakeholders and takes an over-all approach to the development of palliative care services in Malta at the national level.

Palliative care in Malta is presently being funded through a mixed system of, public, private and charitable financing sources. For more than twenty years, Government has been commissioning several palliative care services to Voluntary Organisations. Notable investment has been made in specialist palliative care with the opening of the SAMOC hospital, however, this caters only for oncology palliative patients. Major new investment is needed to strengthen and expand current services, to meet the palliative care needs of people with cancer as well as other chronic debilitating conditions in both hospital and community settings. This need is accentuated for the development of community services. There is a need for a separate protected budget specifically for palliative care. A cost-benefit analysis needs to be undertaken to guide decisions on how the service should be delivered and funded, whether we should opt for a commissioning exercise for some of the services, especially community-based services and palliative care beds, and to what extent we should invest more in-house.

#### **Recommendations:**

- **Establish a governance structure to oversee the implementation of this strategy and ensure the coordination of palliative care services at the national level. It would be**

responsible for leading the process of integrating palliative care into all levels of care, offering advice for the development of palliative care services and implementing quality improvement initiatives.

- All proposals for specialist palliative care services including capital investments, in service plans and service agreements should be made within the context of this strategic plan.
- Allocate a separate protected budget specifically for new initiatives and developments in palliative care.
- Undertake a cost-benefit analysis to guide decisions regarding how the service should be delivered and funded and assess the role that commissioning will have to play.
- Ensure that Government works in partnership with voluntary service providers through established service agreements linking funding by Government with an agreed level and range of services to be provided by the voluntary organisation.

### **3.6.2. Anticipating palliative care needs and improving continuity of care across services and care settings**

#### **3.6.2.1. Identification of palliative and end-of-life care needs.**

Limited or delayed palliative care provision increases suffering for patients and families as their needs are not adequately met. Furthermore, it leads to higher health care costs due to unnecessary hospital admissions, lengthier hospital stays and inappropriate recourse to expensive emergency services and treatments (6).

Best practice examples to enable the identification of patients in need of palliative care as early as possible include the development and use of tools such as the Supportive & Palliative Care Indicators Tool (SPICT) in Scotland (77) and the Gold Standards Framework (GSF) in the UK (78). These tools enable the adoption of a more proactive approach to health care planning and may prompt the initiation of a conversation about treatment preferences.

In the UK and Ireland, the use of the GSF is part of the Quality and Outcomes Framework (QOF) at primary care level. The QOF involves the establishment of a palliative care registry within GP practices and regular multi-disciplinary team meetings to discuss the planning and

delivery of care for patients, the outcomes of which are recorded in the registry. Palliative care registries, which list identified patients, draw attention to individuals, families and carers who may require additional support and prioritisation. Using the ‘surprise question<sup>6</sup>’ to predict main areas of need and support required, patients are categorised based on their needs:

- Stable year plus prognosis
- Unstable/advanced disease months prognosis
- Deteriorating weeks prognosis
- Final terminal care days prognosis
- After care (35)

Primary care services in the community are best positioned to identify palliative care needs as early as possible (39). Empowering family doctors to better assess palliative care needs at the primary care level should enhance the delivery of palliative care in the community setting.

The above-mentioned standardised tools are already in use by some doctors in Malta, mostly family doctors and geriatricians, however this practice is not widespread.

#### **Recommendations:**

- **Assess the suitability of using a standardised tool such as the GSF or SPICT tool in the local setting for early identification of patients with palliative care needs. Special consideration should be given to the use of such tools in the primary care setting.**
- **Consider the development of a plan to empower and incentivise local GPs to identify palliative care needs as early as possible at primary care level.**
- **Assess the feasibility of introducing a palliative care registry.**

### **3.6.2.2. Palliative care needs assessment and care planning**

#### **Palliative care needs assessment**

A palliative care needs assessment goes beyond the physical needs of the individual and includes the social, mental health and emotional, and spiritual well-being of the patient, their family and carers. Needs assessments should be repeated when needed to identify and

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<sup>6</sup> The surprise question ‘Would you be surprised if this patient were to die in the next 6-12months’, if in the affirmative, it is used as a trigger for palliative care.

address the changing needs and circumstances of patients, their families and carers. For example, repeat assessments are required at key transition points, such as at discharge from hospital or when the goals of treatment have changed (35,79).

Needs assessments could be supported using validated tools, however, this would necessitate appropriate assessment of the feasibility of adopting the use of such a tool in the local setting. All health professionals who may need to initiate discussions about the need for palliative and end-of-life care should have the knowledge, skills and competence to do so sensitively (section 3.5.1).

### **Individualised care plans**

An individualised patient-centred care plan should be drawn up for every patient identified as having palliative care needs and should be based on the outcomes of a needs assessment. A care plan should include information on all components of a patient's care including: diagnosis, medications, carers and next of kin, understanding, function and cognition. The patient together with their family and carers should be involved as much as possible in care planning.

Certain illnesses may affect to varying extents people's ability to understand speech and written information and/or their ability to express their thoughts through speaking or writing. Some examples include: stroke, neurological diseases, head and neck cancers, and brain tumour. Some people may have disabilities such as deafness or blindness, some may have intellectual disability and others may be unable to communicate due to language barrier. Health care professionals' skills to deal with patients' specific communication needs must be addressed (Section 3.5.1). At times, support from speech and language pathologists, interpreters and sign language interpreters may be necessary.

It is imperative that care plans can be readily accessed in a timely manner by all health professionals involved in the care of the patient, in all health care settings; community, long-term care, acute care hospitals and specialist palliative units or hospices. This would enhance continuity of care.

### **Advance Care Plans**

Individualised care plans may also include elements of advance care planning whereby the patient's wishes and values for their end-of-life are reported in a document that moves with the patient. With disease progression and deterioration of cognitive and physical function over time, some patients' decision-making capacity may also decline. The process of advance care planning can change as the patient's circumstances also change, with a view toward continuing to involve the patient in the planning process. The information in the advance care



planning document can include patients' preferences regarding how and where their end-of-life care is provided. Involvement of persons who are, ideally, chosen by the patient him/herself as part of the advance care planning process helps to assist the patient in the process of filling out an advance care plan. The advance care plan can then be activated as directed by the patient him/herself. It is advisable that filling out an advance care plan is done with the involvement and guidance of the doctor-led multidisciplinary team. Medical professionals taking on this capacity will require specific training or competence. In addition, the medical team involved in the end-of-life care when the patient's decisional capacity is lost, would do best to consider the past-expressed patient's wishes in the advance care plan. Complex ethical dilemmas may arise when using advance care planning as described in section 3.6.2.3.

An Advance Care Plan is not legally binding, however will provide a guide as to the patient's wishes. The plan can change as the patient's situation changes (28). Advance Care Plans should be distinguished from Advance Directives which are "instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity" (80). Unlike Advance Care Plans, Advance Directives are legally-binding (28). Advance directives are not currently authorised under Maltese legislation.

Advance care planning already happens in Malta to a certain extent by GPs when for example the decision is taken for a patient to die at home. This happens mostly when the GP has known the family for quite some time. In such instances, the GP communicates with relatives and explains when 'time has come'. Explaining and discussing the futility of treatment with relatives in their own time may lead to a decision to stop treatment. This is very unlike the situation in an acute hospital setting where decisions are mostly made during ward rounds without sufficient time for discussion and by doctors who barely know the patient (28).

#### **Recommendations:**

- **Ensure that health care professionals have the necessary training, knowledge and skills to undertake palliative care needs assessments and deal with patients' specific communication needs.**
- **Encourage and enable the use of individualised care plans which can be readily accessed in a timely manner by all health professionals involved in the care of the patient, in all health care settings.**
- **Introduce the use of advance care planning. This is best introduced gradually and should be preceded by the establishment of appropriate guidelines and protocols; the provision of adequate training to health care professionals; adequate support structures**

**(including legal) in place; and monitoring and evaluation structures in place to ensure the proper application of advance care plans.**

### **3.6.2.3. Complex ethical dilemmas surrounding end-of-life decisions**

Various complex ethical dilemmas may arise when it comes to end-of-life decisions. A common example is the dilemma regarding if and when nutrition and hydration should stop towards the end-of-life. Many doctors have difficulty dealing with such issues due to lack of knowledge and understanding of what is morally acceptable and legal when it comes to stopping treatment which is considered futile<sup>7</sup> or extraordinary<sup>8</sup>.

Recently, a set of guidelines to shed light on such ethical dilemmas were put together as part of a project conducted jointly by three Faculties within the University of Malta: the Faculty of Medicine & Surgery, the Faculty of Laws for legal guidance and the Faculty of Theology for guidance on what is accepted moral practice (28).

#### **Recommendations:**

- **Provide opportunities for health care professionals, hospital administrators, patients and relatives to further their knowledge and understanding of what is morally acceptable and legal when it comes to dealing with complex ethical dilemmas surrounding end-of-life care issues.**
- **Provide access to clinical ethics support to all staff as appropriate to his/her role**
- **Ensure there is an established and accessible Do Not Attempt Resuscitation (DNAR) policy across all health care settings, which includes a clear pathway toward advising the patient and any representatives the patient him/herself nominates or that are otherwise appointed according to law about any DNAR in relation to the patient's care.**

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<sup>7</sup> Futile treatment: Treatment which is not considered by the doctor to be in any way beneficial to the patient.

<sup>8</sup> Extraordinary treatment: This is not futile treatment but simply treatment which may be prolonged with some benefit, albeit sometimes at some cost to the patient.

### 3.6.3. Planning and delivering palliative care across services and care settings

The quality of care provided is dependent both on the effectiveness of each individual service and the coordination between them. Lack of coordination between the services disrupts continuity of care, may lead to unnecessary admissions or prolonged hospital stays, and may have a negative impact on the quality of life of patients and their families. Uncoordinated services could also result in the duplication of services to some patients and lack of services to others (4). The provision of specialist palliative care should be structured in a way that permits patients to change from one service to another according to clinical needs or personal preferences (34).

#### **Coordination needs to be present at various levels:**

- Coordination within an individual team.
- Coordination between teams working in the same setting e.g. a heart failure team and a specialist palliative care team in the acute hospital setting.
- Coordination across different settings e.g. when a patient is discharged from hospital to the community.

Certain initiatives that have been described elsewhere in the strategy can contribute to enabling communication and coordination across care providers and care settings. These include:

- The development of protocols delineating the roles, responsibilities and referral criteria for hospital palliative care support teams and home palliative care teams (sections 3.5.2.2 and 3.5.2.3)
- Care plans that are readily accessible by all health care professionals involved in the care of the patient, in all health care settings (section 3.6.2.2)
- Investment in information systems to enable communication flow across care settings (section 3.6.6)

#### **In addition, the following recommendations are also being made:**

- **Promote and enable where feasible regular multidisciplinary team meetings in both community and hospital settings to enable the transfer of information between professionals, discuss problems and explore potential solutions for the improvement of patient care.**
- **Develop protocols delineating clear palliative care referral pathways as well as criteria for admission and discharge at all levels of care.**

- **Make arrangements where feasible so that palliative patients requiring the services of several disciplines within the hospital may be provided with such services during the same appointment or admission.**

### **3.6.3.1. The role of the key worker or case coordinator**

The key worker or case coordinator can play a key role in coordinating patient care and ensuring continuity of care across care settings, including within and between care teams. The allocation of a key worker to a particular patient is already in practice. Some of the duties include:

- Acting as a point of contact for the patient, family and carers;
- Providing timely information that is tailored to the individual's needs and understanding;
- Coordinating the end-of-life care journey and, where appropriate, ensuring interventions take place in a timely manner;
- Enabling the coordination and transfer of information across care settings and care teams

The key worker can be one of the members of an existing team e.g. GP, nurse, social worker or other appropriate person. Key workers should undergo role-specific training to help them perform this coordinating role. The key worker may change over the course of the individual's illness due to the nature and complexity of the condition and the disease/decline trajectory (35). Hospice Malta appoint a Palliative Care nurse as a key worker to each of their patients.

At present in Malta, there are a number of site-specific nurse navigators deployed within the Cancer Care Pathways Directorate whose role is to follow-up patients throughout their cancer care journey from initial referral for assessment to cancer diagnosis and treatment, followed by survivorship and palliative care. A new Case Management Service was introduced by Active Ageing and Community Care (AACC) in 2023 with the aim of providing more support to persons living in the community and who are experiencing difficulty coping with one or more chronic conditions. A case manager will be coordinating the care to address these persons' needs in the community (81).

#### **Recommendations:**

- **Assign a key worker or case coordinator who has undergone role-specific training, to as many patients as possible with palliative care needs.**

### 3.6.3.2. Discharge planning

Discharge planning should be encouraged in the hospital setting to facilitate the seamless transfer of patients to the community. Delays in or failure of proper communication and information exchange between hospital staff and community-based health care providers, as well as delays in acquiring the necessary medications and equipment prior to discharge, may lead to delayed discharges which in turn blocks hospital beds unnecessarily. It may also have a negative impact on the quality of life of patients. Furthermore, a more planned approach to discharge might also reduce unplanned re-admissions (62).

Liaison services are important to facilitate the transfer of patients from the hospital to the community. A focal nurse in palliative care can be the key person to liaise with community health care professionals, ideally by contacting them directly in advance of a patient's discharge to discuss changes in medication and to clarify any other issues relating to patient care, such as identifying aids or appliances that may be required. Early notification of discharge is essential, so that health care professionals in the community and the family can make the necessary preparations ahead of the patient's return home.

On discharge from hospital, palliative care patients should be provided with a detailed discharge summary including information on any medication or supplies necessary. It should also include information on the degree to which patients and their relatives are aware of their diagnosis.

The discharge process may need to be fast-tracked for patients with advanced disease and poor prognosis, especially if it is their wish to die at home. The timely availability of medical equipment, home modifications, and the necessary permits for medications are important limiting factors to the discharge process. These issues are addressed in section 3.6.5.

#### **Recommendations:**

- **Strengthen discharge liaison services to enable the seamless transfer of patients from hospital to community whilst avoiding delayed discharges.**
- **Develop adequate protocols for discharge planning, addressing issues related to communication and transfer of information and access to medicines and equipment.**
- **Discharge summaries should be detailed and include information on medications, supplies and equipment needed as well as information on the degree to which patients and their relatives are aware of their diagnosis.**

## 3.6.4. Integrating palliative care in the acute hospital setting

### 3.6.4.1. Fostering a culture that values the role of palliative care

Professionals working in the acute hospital setting encounter death and issues related to grief and bereavement daily. However, acute hospitals tend to be mostly focused on the provision of curative treatments with less prominence given to palliative, end-of-life and bereavement care. With the majority of deaths occurring at MDH, this certainly has a detrimental effect on the quality of care provided to numerous patients nearing the end-of-life, along with their families and carers. Indeed, during consultations with stakeholders including patients, carers and professionals, a stark distinction was highlighted between the care provided to patients nearing the end-of-life in MDH and that provided in SAMOC. The patient-approach adopted by health professionals working in SAMOC was described as far more all-embracing and compassionate than that adopted on acute hospital wards in MDH. Instances were also described of patients dying on hectic hospital wards, where the environment was inappropriate for grieving relatives.

This creates inequalities between settings due to a poorer quality of care provided to palliative care patients residing at MDH as opposed to SAMOC. There also exist inequalities by diagnosis due to an overall poorer quality of palliative care given to patients living with chronic non-cancer conditions as opposed to care given to oncology patients whose palliative care needs tend to be more recognised.

A number of recommendations described elsewhere in the strategy are also conducive to the integration of palliative care in the acute hospital setting and contribute to the improvement of the quality of palliative care being provided. These include:

- Provision of adequate education and training with respect to communication, assessment of needs and symptom management (section 3.5.1)
- Establishment of hospital palliative care teams who play a crucial supportive, advisory and educational role (section 3.5.2.2)
- Care plans that are readily accessible by all health care professionals involved in the care of the patient, in all health care settings including the acute hospital (section 3.6.2.2)
- Provision of clinical ethics support to all staff dealing with end-of-life care issues as appropriate to his/her role (section 3.6.2.3)

In addition, the following recommendations are also being proposed:

### **Recommendations:**

- **Develop and implement a quality improvement plan for the delivery of palliative and end-of-life care at MDH, GGH and other acute care settings.**
- **Encourage the practice of holding multi-disciplinary team meetings for specific specialties (e.g. medical specialties such as cardiology and respiratory medicine), or for certain wards such as the Medical Assessment Unit (MAU), with involvement of palliative care specialists, to foster a proactive and holistic approach to identifying and caring for patients nearing the end-of-life.**
- **Establish protocols for the relocation of patients nearing the end-of-life to quieter wards or single rooms where possible.**
- **Develop standard clinical guidelines for the management of common symptoms in palliative care to support prescribing health care professionals. Guidelines for pain management are already in place.**
- **Develop evidence-based clinical guidelines on the care of adults in the last few days of life for use in the local setting**

### **3.6.5. Access to medicines and equipment**

Palliative care patients with advanced disease may have a limited life expectancy, such that delays or overly burdensome procedures to access medicines and equipment are considered inappropriate and should be reduced as much as possible.

Upon discharge from hospital, a patient may need to be provided with the necessary equipment and supplies in the home such as: hospital bed, pressure relieving devices, syringe infusion pumps, incontinence products and dressings. The availability of such items may be limited, and access may be difficult especially during weekends. Furthermore, the process of acquiring the necessary permits to obtain such equipment can be lengthy and overly bureaucratic. Managing a patient at home also necessitates a visit by an occupational therapist to advise on the need for suitable aids and, if necessary, modifications to the home to make it more suitable to the patient's needs.

Access to medications routinely prescribed in palliative care are contained in the List of Essential Medicines from the World Health Organization (82). Medication required to ensure comfort at the end-of-life is often complex and may include controlled drugs such as strong opioids, including injectable formulations for use with a syringe pump. Patients requiring

palliative care often need strong analgesics in large doses for the relief of pain and other symptoms. The process of acquiring the necessary permits for the provision of certain medications can be lengthy and bureaucratic. Certain medications may not be available as routine stock by community pharmacies and must be ordered, hence communication between hospital-based palliative care specialists and the community pharmacist is essential. Such communication is also necessary in instances where community pharmacists require support regarding the use of certain medications that they do not routinely dispense.

Presently, there is no clinical pharmacist attached to the Palliative Care Unit at Mater Dei Hospital who can play an important role in supporting pharmacists and GPs working in the community which includes patients' own homes, care homes and long-term care facilities. Furthermore, the current medicines formulary needs to be reviewed and updated based on latest treatment guidelines and scientific evidence on cost-effectiveness.

Timely access to essential medicines used in palliative care in all health care settings is considered crucial, as is the need for health care professionals to have the necessary education, skills and knowledge that lead to the confidence to both prescribe and administer these drugs (section 3.5.1.).

#### **Recommendations:**

- **Review and streamline the various procedures and protocols that are currently in place for palliative care patients to access medicines, equipment and medical supplies as and when required.**
- **Prioritise the recruitment of a clinical pharmacist within the palliative care unit at MDH to act as a focal point for community pharmacists and general practitioners caring for palliative care patients.**
- **Establish better communication channels between: hospital-based pharmacists and palliative care specialists, community pharmacists, and general practitioners to ensure that patients receiving palliative care have access to all necessary medications as and when required.**
- **Undertake a review of the medicines formulary and assess for the need to include new medicines to enhance the therapeutic options available. This should be done based on latest treatment guidelines and scientific evidence on cost-effectiveness.**



### 3.6.6. Information Systems

Information systems are crucial to enable communication flow across care settings for the delivery of high quality, integrated palliative care. Integrated electronic records can support access to individual care plans by health professionals involved in the care of the patient, in both community and hospital-based settings. This would enable access to patient information out-of-hours, allow timely intervention and continuity of care across care settings. This must happen within the right legal framework, with data security and confidentiality guaranteed at all times. Progress is underway in this area, with Primary Health Care and SAMOC already making use of fully-fledged electronic patient records systems.

#### **Recommendation:**

- **Enable access to patient care plans and other medical records by health professionals involved in the care of the patient across different care settings using the appropriate information systems with due safeguards in place as provided for by the data protection legislation.**

### 3.6.7. Quality improvement and building research capacity in the sector

#### **Quality improvement and monitoring performance**

Continuous improvement of the quality of care may be defined as a systematic process of evaluation and improvement of the quality of the services provided. Quality improvement in palliative care is no different from quality improvement in health care as it has been described in Council Of Europe recommendation R(97) 17 and its appendices (83). However, some of the particular dimensions of palliative care such as the prevailing importance of patient preferences, the family as the unit of care, and the importance of spiritual and existential issues, make for specific aspects of quality improvement in the sector (19).

There are multiple dimensions to quality improvement systems. For instance, the application of clinical and service evaluation methods such as audits, necessitates the prior development of quality standards against which it is possible to evaluate practice. Another important domain is the development of evidence-based practice guidelines whose implementation and effects need to be adequately measured and monitored. Furthermore, health care information systems need to be in place using relevant care and process quality indicators (83).

The application of quality improvement systems and performance measurement in palliative care are lagging behind. A set of indicators needs to be developed and agreed to in order to be able to monitor progress with respect to the implementation of the proposed recommendations in the strategy and to measure performance in the palliative care field. The development of such a monitoring framework will draw upon established indicators as per Brief Manual on Health Indicators Monitoring Global Palliative Care Development (84) and the WHO's set of actionable indicators for assessing the development of palliative care worldwide (85) amongst others.

In order to implement proper quality improvement systems, the setting up of a good governance structure is a crucial prerequisite.

### **Research**

Research usually has as its primary aim the improvement of quality of care for patients and it will therefore be discussed alongside quality improvement in palliative care. Indeed, research is considered to play an essential role in the planning, development and improvement of palliative care services (6). Unfortunately, published research and evidence on palliative care in Malta is very limited. Domains where research is particularly lacking include: population needs for palliative care including the paediatric population and people with chronic conditions other than cancer; service provision and utilisation; patients' and carers' attitudes and knowledge about palliative care; and mental health of patients, their families and informal carers, and of professionals providing palliative care. It is deemed important for there to be adequate resources and opportunities for academic researchers and health care professionals to engage in research and audit on palliative care.

### **Recommendations:**

- **Establish quality standards for palliative care against which practice can be monitored and evaluated.**
- **Develop evidence-based clinical practice guidelines for palliative care.**
- **Develop a set of indicators to monitor progress with respect to the implementation of the proposed recommendations in the strategy and to measure performance in the palliative care field.**
- **Encourage and facilitate greater participation in palliative care research at both the local and international levels to inform future policy, planning and delivery, drive up quality and improve outcomes in palliative care.**

- **Ensure there is a good governance structure in place to implement adequate quality improvement systems, monitor the implementation of the strategy as well as measure performance in the palliative care field.**
- **Ensure the routine collection of data and audit on palliative care.**

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