WE ARE MACMILLAN. CANCER SUPPORT

PALLIATIVE AND END OF LIFE CARE FRAMEWORK

2012-2014

Contents

Introduction

Approximately half of adults live for five years or more after a cancer diagnosis; half do not[1]. Our ambition is to provide support to every person living with cancer, every step of the way. Palliative and end of life care is an important part of the experience of many people diagnosed with cancer, and their friends and relatives.

Macmillan Cancer Support has always had an active involvement in palliative and end of life care. However, in recent years, with the development of the survivorship initiative, there is a misperception among some professionals and members of the public that we have moved away from palliative and end of life care. There is often confusion about the roles of the various voluntary organisations in this field (see **Appendix 3**).

This document outlines the Macmillan Palliative and End of Life Care framework that we've developed. It aims to illustrate our continuing commitment to palliative and end of life care, describing our historical involvement, what we are currently doing and our plans from 2012 to 2014.

In order to develop the framework, a major scoping exercise and consultation was undertaken including:

- a review of the research and national strategies
- a UK wide survey of Macmillan professionals
- a UK wide survey of Macmillan Service Development teams
- a focus group for Cancer Voices representatives
- meetings with regional and national teams.

This framework draws together:

- what good palliative and end of life care looks like
- what we currently do which supports provision of good palliative and end of care
- what more we plan to do over the next two to three years to support further improvements in palliative and end of life care for people affected by cancer.

'Palliative and end of life care is an important part of the experience of many people diagnosed with cancer, and their friends and relatives.'

Our history in palliative and end of life care

In 1911, Douglas Macmillan set up what was originally known as the Society for the Prevention and Relief of Cancer. He started the society after feeling traumatised and helpless, watching his father die from cancer with so little support. The grants programme was set up soon after the charity was founded.

The iconic Macmillan nurse has been around since the 1970s – and is a great symbol of Macmillan's involvement in all aspects of the cancer experience. Our work to improve cancer environments has also been greatly beneficial. In fact, we were involved in building hospices and funded the early hospice community teams, as well as hospital support teams.

Macmillan was instrumental in the development and initial rollout of the Gold Standards Framework (GSF), in its early phases. GSF is a systematic evidence-based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting. GSF improves the quality, coordination and organisation of care in primary care, care homes and acute hospitals. This enables more patients to receive the type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation.

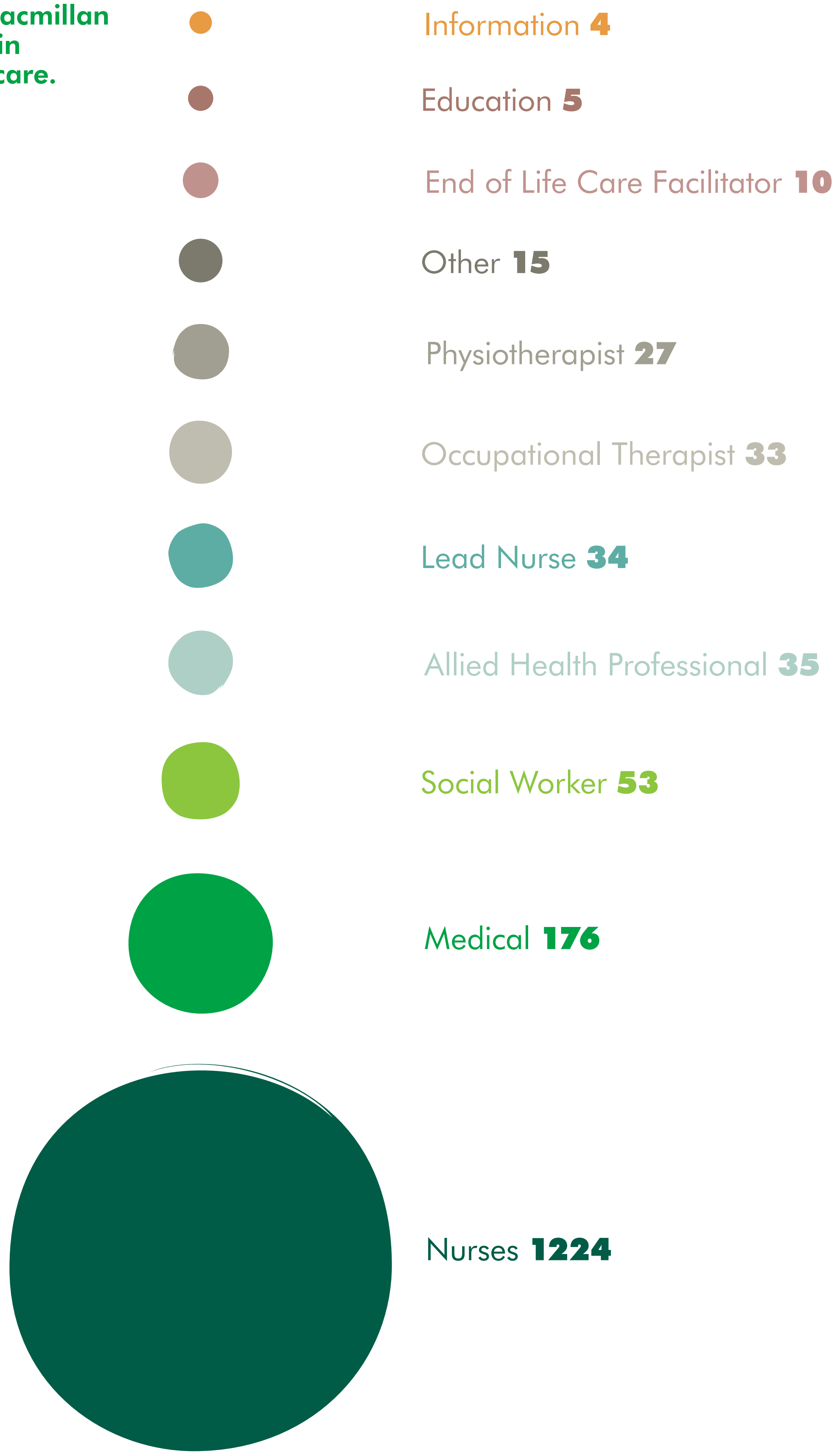
The current position

The most recent in depth analysis of Macmillan professionals showed a total of 1616 working in palliative and end of life care, which is 32% of our total Macmillan workforce.

The majority of our professionals in this field are specialist palliative care nurses, as demonstrated in table 1.

In 2010 28% of our charitable spend of £96 million was on palliative and end of life care. These funds went towards professional posts, projects and other elements of our work such as campaigning, grants and the Macmillan Support Line. We also currently create and provide a range of information resources such as *End of life care: The facts* and *Hello and how are you?* **(see Appendix 1)**.

Table 1. Numbers of Macmillan professionals working in palliative and end life care.



Our vision

Macmillan's ambition is to reach and improve lives of everyone living with cancer and inspire millions to do the same. We have developed 9 outcomes based on what people affected by cancer tell us they want to be able to say. These outcomes are absolutely central to our strategy over the next 20 years, as we want people affected by cancer to be able to say these by 2030:

I AM TREATED WITH DIGNITY AND RESPECT

I WANT TO DIE WELL

I KNOW WHAT I CAN DO TO HELP MYSELF AND WHO ELSE CAN HELP ME

I UNDERSTAND SO I MAKE GOOD DECISIONS

I WAS DIAGNOSED EARLY

I GET THE TREATMENT AND CARE WHICH ARE BEST FOR MY CANCER AND MY LIFE

I CAN ENJOY LIFE

I FEEL PART OF A COMMUNITY AND I'M INSPIRED TO GIVE SOMETHING BACK

THOSE AROUND ME ARE WELL SUPPORTED

Nearly all of our 9 outcomes apply to people with palliative care needs, ie care is personalised, care is coordinated, people are helped to make informed decisions and plans, carers are supported, and there's an emphasis on quality of life. The last outcome, 'I want to die well', is central to our end of life strategy and our vision, in support of it, is:

People who are nearing the end of their life will be supported to make decisions that allow them and their family or carers to be prepared for their death. Their care will be well coordinated and planned so that they die in the place and in the way that they have chosen.

National strategies
The four nations of the UK already have end of life care strategies. These are based on the best available evidence and research. In developing our framework we were keen not to replicate the good work already done. However, it was useful to use these strategies as a basis to review what we currently do and what we could do in relation to each element.

Although there are vast differences between each of the UK nations, there are common themes identified in the strategies.

KEY THEMES

The following section of this framework sets out the work that Macmillan Cancer Support is doing in relation to each theme.

- Identification of people approaching the end of life and initiating discussions
- Care planning
- Coordination of care
- Delivery of high quality services in all locations
- Management of the last days of life
- Support for carers, both during a person's illness and after their death
- Raising the profile of death and dying
- Strategic commissioning

Identification of people approaching the end of life and initiating discussions

Identification of people who are approaching the last year of life is an essential first step in providing effective end of life care services[2]. Identifying those who are likely to die within the next year and initiating the necessary, and often difficult, conversations is complex and requires considerable skill and experience.

We already have a range of products and services to support professionals in identifying patients as they enter the end of life phase and discussing their individual needs and wishes. These include the Treatment Summary and the Macmillan Palliative Care Review Template.

Learning and development

We continue to support professionals in developing and extending the necessary skills and knowledge through learning and development resources. We enable them to work with education institutes, researchers, professional bodies and Macmillan professionals, such as Macmillan GPs. Some key examples of these resources are set out in **Appendix 1**.

Good communication skills are essential for professionals initiating difficult discussions about preferences for end of life and for supporting patients and carers as they consider their decisions. NICE guidance stresses the importance of good face-to-face communications between health and social care professionals and patients and their carers. Therefore, our Learning and Development team have reviewed communication skills of professionals and psychological support across the UK and developed a position statement.

Advanced communications skills training courses are run frequently but are aimed at the specialist healthcare workforce. SAGE and THYME is a model developed by a Macmillan Nurse Consultant in Palliative Care. It is basic communication skills training aimed at providing level one psychological support to patients and their carers. Throughout 2012 Macmillan Learning and Development team will be testing out this model across the UK. The aim will be to work towards a 'train the trainers' approach, working with professionals who will then cascade training across their organisations to the wider cancer workforce and generalist staff.

Enhancing communication skills is also a key part of the Macmillan GP role and job specification. Macmillan GPs and GP Advisers have done a number of pieces of work to improve communication skills including sessions at conferences and workshops and development of communication skills models in Scotland.

We believe that End of Life Care Facilitators are an excellent resource to support the spread of best practice in end of life care. We currently have 10 Macmillan End of Life Care Facilitators across the UK and in Northern Ireland we have 9 professionals in similar roles with varying titles such as educator or palliative care service improvement lead. In England there is national network of facilitators with more than 300 members, who have a virtual online network and regular conferences and events. As there was no equivalent in the Celtic nations, we have given a financial contribution to the National End of Life Care Programme team to allow those working in the Celtic nations to be part of this network.

Another network that we have financially supported is the UK wide Palliative Care for People with Learning Disabilities network. The PCPLD Network is a voluntary organisation that started when a small group of learning disability and palliative care professionals came together. They were concerned by their experience that people with learning disabilities, who were facing a life-limiting illness, did not seem to access the same services or receive the same quality of service as the rest of the population. The network now has 200 members including a few from overseas. As well as providing the network with financial support, we are currently planning a joint project with them, and including Mencap and Marie Curie Cancer Care.

Research

Macmillan Palliative and Cancer Care Research Collaborative (MacPaCC) was established to understand and improve cancer care, palliative care and support for cancer survivors. The group's members have wide-ranging expertise and are potentially highly influential. The group currently manages five research projects which will be used to inform service development and learning and development in palliative and end of life care. MacPaCC is currently funded until the end of 2012. During 2012 we will work with Macmillan's Intelligence and Research (I&R) team to increase internal and external awareness of MacPaCC's work programme (internally via the Palliative and End of Life Care Steering Group and Healthcare PMG, externally collaborating with communications colleagues). We will also consider in 2012 whether to recommend that the group is funded beyond 2012. We will need to assess whether it strengthens the research base for our framework and the priorities that emerge from the corporate route map in support of the nine outcomes.

Commissioning

The National End of Life Care team in England has identified key data items that should be recorded in palliative care registers. These reflect many of the steps necessary in providing good palliative and end of life care. Included in this are the ability to initiate the conversation about end of life and recording preferred priorities for care and place of death. Our policy team will use their influence in the coming year to push for the recording of this key data to be included as an indicator in the Commissioning Outcomes Framework. This would help to ensure that locality-wide registers are developed and used to promote best practice. It will also enhance choice for patients and carers towards the end of life, as well as providing comparable data from different registers. This data can then be used to track activity and performance.

Quality and Outcomes Framework (QOF) points

The QOF is a means by which GPs earn additional payments for undertaking specific activities, such as reviewing their cancer patients. There are comparatively few QOF points available for cancer or palliative and end of life care. We will continue to push to make the available points drive improved care. For example, we aim to ensure that every person on a GP's end of life care register is reviewed at least once a month, rather than every three months – the current requirement.

‘Patients are supported to think, for example, about decisions they may not be able to make later due to loss of mental capacity.’

Care planning: Advance Care Planning (ACP)

Alongside general care planning (designed to improve care and coordination at all points of the cancer patient’s pathway and supported, for example, through the National Cancer Survivorship Initiative) there is also a need to promote specific discussions with patients and carers about their preferences surrounding the end of life. These include preferred type of care, limits on treatment (eg ‘do not resuscitate’) and place of care and death. The terminology and law around this type of planning and recording of wishes varies between the UK nations.

Advance Care Planning focuses on establishing a person’s wishes around care at end of life and usually takes place as their condition is expected to deteriorate. Patients are supported to think, for example, about decisions they may not be able to make later due to loss of mental capacity. The conclusions are reviewed regularly and shared with those involved in a patient’s care.

There has been a particular drive in England to promote Advance Care Planning but uptake is variable and it previously received less focus in the other UK nations. However, there is an increasing focus, particularly in Northern Ireland, where all the Trusts are putting policies in place and running educational sessions. In Scotland the term Advance / Anticipatory Care Planning is used.

There are several different tools which are used to support ACP but few of them contain all of the necessary elements to promote best practice and maximise choice for patients and carers. Through our Healthcare and Information teams, we are currently developing an Advance Care Planning tool which will reflect best practice and will be Macmillan-branded. We will promote this to Macmillan Professionals and make it available via our information and support teams. As this will be available in information centres and to general public on our website, it is hoped that this will encourage people to start the process themselves, rather than wait for a health professional to initiate the conversation. The aim is that this tool will empower patients to make decisions themselves.

In some instances Advance Care Planning does not take place due to health professionals’ lack of confidence or ineffective communication skillls. Good communication skills are central to effective Advance Care Planning so there is a clear link between ACP and the communication skills training pilots described above.

The Healthcare and Policy Teams will develop campaign for the use of Advance Care Planning to ensure patients’ and carers’ wishes are discussed, recorded and acted upon.

Coordination of care

Coordination of care is repeatedly cited as a key problem for cancer patients and carers. It stands to reason therefore that coordination of palliative and end of life care is no less important or problematic.

In a survey of Macmillan regional teams, 75% of respondents said that one of the greatest barriers to effective end of life care was the lack of coordination of care, alongside lack of access to care out of hours and lack of support for carers.

One-to-one support

One way in which we are aiming to improve coordination of care is through our One-to-one support implementation project. In 2010 the Department of Health commissioned Frontier Economics to model one-to-one support for cancer patients in England[4]. Macmillan extended this work to estimate an indicative gap associated with one-to-one support for cancer patients across all cancer sites and for the whole of the UK. We are looking to fill that gap with both specialist and generalist roles, including palliative and end of life care and this should significantly improve coordination of care. Within the Macmillan Workforce Strategy, we identified four new roles that we felt would augment current workforce roles. This would go towards ensuring that patients have access to the right person with the right skills at the right time.

Over the next two years we will pilot the Macmillan Support Worker role within palliative and end of life care teams to improve coordination of care. The remaining three workforce roles we are piloting will provide generalist palliative and end of life care. Part of these roles will be to determine local palliative and end of life care pathways and the boundaries between generalist and specialist care.

24/7

In 2010 we produced the **Always There report**[5]. Only 56% of the PCTs in England who responded reported having a full 24/7 community nursing service (ie district nursing). We have been actively campaigning for 24/7 care and are continuing to do so in 2012. We have agreed to work with more partners, including the National End of Life Care Programme, National Council for Palliative Care, Royal College of Nursing, Help the Hospices and Marie Curie Cancer Care to expand our campaign.

Social care

In addition to the difficulties in effective coordination between health services, there are also problems in coordination of care between health and social services. Macmillan supports around 170 social work posts, approximately 41 of which are specifically related to palliative care. We've appointed a Social Care Programme Manager who is reviewing the links between social care and palliative and end of life care going forward. They will make proposals to enhance the coordination of health and social care across the patient pathway, including at end of life. There may be opportunities, for example, to learn from Northern Ireland, which has a more integrated health and social care system.

Integration of health and social care is one of the main issues that will be covered in the Government's forthcoming Social Care White Paper. This will give us a key influencing and campaigning platform to promote better integration of health and social care. It will also allow us to give a voice to other key recommendations, such as free social care provision for those on locality-wide palliative care registers, as recommended in the Palliative Care Funding Review. And we will be working closely with the National End of Life Care Programme in England to align our social care projects with their work, such as their Routes to Success series, which includes recommendations around social care.

Improving choice at the end of life for people affected by cancer has always been a core aim of Macmillan's work, and in the last few years it has become a major focus for our influencing work. However, another aspect of end of life care, which is crucial to making choice a reality, is ready access to social care services.

Last year the Palliative Care Funding Review (PCFR) in England recommended that social care should be fully funded for those on an end of life care register. The Review made clear that this was critical for improving integration between health and social care and for ensuring that people are properly cared for in the community.

We will try to influence the White Paper in England to support free social care at the end of life. Macmillan wants all patients who are on an end of life care register to have access to free social care. People are generally placed on an end of life care register in their last few months of life and this would help to enable them to die at home if they so choose.

Better use of end of life care registers

Macmillan wants every cancer patient to have the opportunity to be put on an end of life care register. Registers record people's preferences for where they would like to be cared for at the end of life and therefore help enable people to die in the place of their choosing. Being placed on an end of life care register would also trigger a person's eligibility for free social care.

In Scotland there is already a well-established system for registering patients approaching the end of life. The information from practice-based registers is accessible via NHS 24 to all professionals who need it, including primary care, secondary care, social care and ambulance services.

Information and financial support

Social care needs are often forgotten or overlooked. The National Cancer Patient Experience Survey[6] shows that only 50% of patients said hospital staff gave them information about how to get financial help or benefits. This is known to be a particularly pressing issue in end of life care. Macmillan currently provides **benefits advice** through local face-to-face services and through the **Macmillan Support Line**. We will continue to provide these services along with the new **Financial Guidance Service** which has recently been launched throughout the UK and our **free benefits and financial support information resources**.

We know that a patient's information needs receive some attention at the point when people are given a terminal diagnosis. But the full complexity of physical, psychological, emotional, spiritual and financial information needs are sometimes missed[7]. To improve the experience of patients and carers following a terminal diagnosis, and around the point of death, we need to increase awareness of the information that might be needed. It's also important to equip people with the skills to elicit these requests.

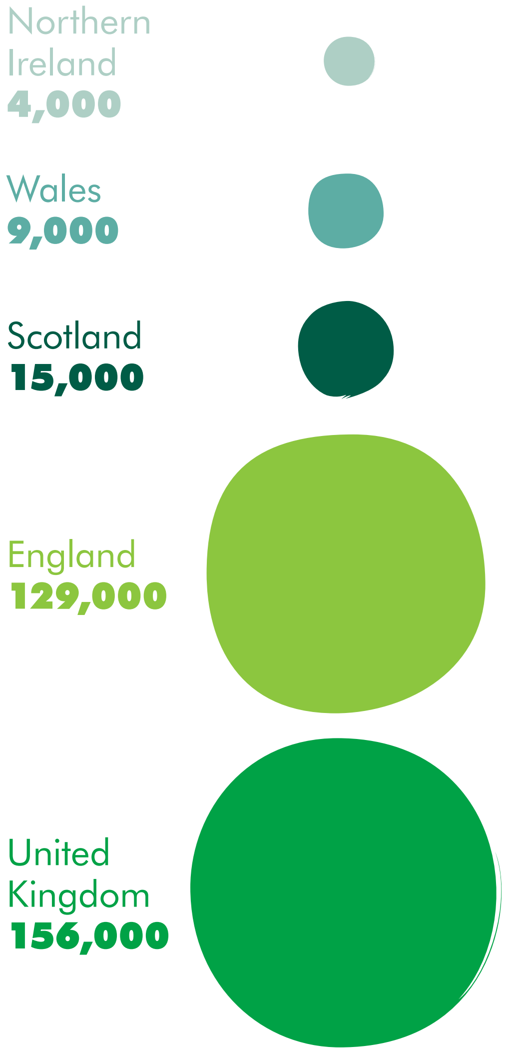
In 2012 the Information and Financial Support team will be scoping the information competences of the wider cancer workforce. This applies to all those who are not information specialists and is intended to improve skills where necessary in 2013. The work will look at key points in the cancer journey, including immediately post diagnosis and end of life.

> 'Macmillan currently provides benefits advice through local face-to-face services and through the Macmillan Support Line.'

Delivery of high quality services in all locations

In 2008, around 580,000 people died in the UK. It is estimated that 42% of these people had had a cancer diagnosis, and of these most died from their cancer[8]. In 2009 around 156,000 people died from cancer in the UK (see Table 2 for numbers by country) accounting for 28% of all deaths. The four most common causes of cancer death in the UK were lung, colorectal, breast and prostate cancers – accounting for nearly half of all cancer deaths (47%)[9].

Table 2. Number of people who died from cancer by UK nation, 2009[10]



With the right support, 73% of people with cancer would prefer to die at home. But only 27% actually do[11]. Everyone should receive the same access to care, support and symptom control wherever they die, whether at home, in hospital, in a care home or in a less common setting such as prison. There are still gaps in services, support and the skills of those caring for people with cancer in all locations.

We asked Macmillan palliative and end of life care professionals what they saw as priorities for Macmillan to support and fund in the future. They identified the top three priorities as:

- reducing both hospital admissions in the last year of life and reducing deaths in hospital
- improving end of life care in care homes
- service improvement.

We are already providing services, learning and development support, and campaigning to support delivery of high quality services in all locations. We have been running palliative care master classes, for example, to share good practice, enhance the necessary skills and increase our engagement with palliative care professionals.

We delivered 16 master classes in 2011 across England, Wales and Northern Ireland for 360 professionals (including Macmillan professionals and the wider workforce). In addition, we held a UK-wide conference with 150 delegates, which made the total number of professionals attending our palliative care events 510. Due to the positive evaluation of these events, we are continuing to run them in 2012 and beyond.

Primary and Community Care

We currently have approximately 200 Macmillan GPs and Primary Care Cancer Leads across the UK. Different models of Macmillan GPs have emerged over time to suit the differing health and social care structures across the UK. However, the overall aim of all Macmillan GPs remains to produce a recognisable improvement in the quality of cancer and palliative care provided by primary health care teams within a local health economy. This is achieved by having protected time to work with all parties involved in cancer care.

In 2012 we will also be adapting the Teesside Palliative Care distance learning course for GPs. This will fill a gap in cancer-specific palliative care training and seek to roll out use of this course in 2012/13.

Across the UK there are various projects which have been funded or part funded by Macmillan. One example of a palliative care project in the community is the Midhurst Macmillan service. Midhurst is an innovative service that delivers active palliative care, using early referral, via a multi-disciplinary community-based service, to patients where they live or in their preferred place of care. It is currently jointly funded by Macmillan and the NHS.

The service adopted a modified version of the Swedish Motala Model for advanced home care. This modelis made up of a consultant-led multi-disciplinary team that aims to provide 24/7 'hands on' care and advice at home, in community hospitals and in nursing or residential homes. The community team provides a range of palliative interventions, including blood / blood product transfusions, parenteral treatments, IV antibiotics, IV bisphosphates, fluids, paracentesis and intrathecal analgesisa.

The service was set up in order to:

- maximise patient choice by providing as much treatment and support in the home/community setting as possible
- reduce acute hospital interventions and inpatient hospice stays
- ensure close working between the NHS, voluntary, charitable and private sectors in order to deliver high quality patient care, in line with recommendations that specialist palliative care is provided as early as possible
- be a sustainable and affordable service for the population within Midhurst and the surrounding areas.

In 2011, Macmillan Cancer Support commissioned an economic and qualitative evaluation of the service, which is now complete. The evaluation found that the service reduces the use of NHS resources and overall has a similar cost to other specialist palliative care services in the area. There are, however, potentially significant cost savings if patients are referred early. The service has also helped to increase choice for those at the end of their life, their clinicians, families and carers. We would like to raise awareness of

this particular model. And we would like commissioners and providers of specialist palliative care to consider a move toward a similar model.

Prisons

In 2011 we held a UK wide conference to showcase innovation and research in end of life care in prisons and we launched the Macmillan Adopted Prison Standards (MAPS). A **report** from this conference can be found on the Learn Zone. We are promoting the use of these standards across the UK to improve standards for people approaching end of life in prisons.

Care homes

A large number of people live, and die, in care homes[12]. Data from the The National End of Life Care Intelligence Network showed that between the periods of 2006 – 2008, the number of people aged over 75 who died in a care home was just over 69,000. This is compared to only 48,000 who died in their own homes and just under a 1,000 who were in hospices. There are almost 21,000 care homes in the UK.

Those living in care homes are usually elderly and potentially vulnerable. Standards of care are variable, ranging from care homes that are accredited as Gold Standards Framework homes to those that are shut down without notice due to poor standards of care. Therefore, end of life care in care homes needs to be improved. This can be achieved by campaigning for improved standards and providing education and support.

Foundations in Palliative Care is a well-regarded Macmillan training package and facilitator pack which is offered as a free resource to care homes. Throughout 2012 our Learning and Development team will be evaluating the Foundations in Palliative Care, to ensure it's effective and inform further development of the resource.

However, there are some areas across the UK where there is no facilitation support available and care homes often have difficulty in implementing training without external skilled support. Service Development Teams report that the use of the existing educational resources in care homes tends to rely on regular facilitation and support because of high staff turnover. We are currently reviewing the types of support available for care homes, such as facilitator posts, link nurse schemes etc, with a view to testing out new models of support in the future.

Out of hours

We have a free of charge out-of-hours and palliative care learning course available on-line. It covers practical guidance and information for people providing and commissioning out-of-hours care, which can also be accessed on the **Learn Zone**. We also have freely available **out-of-hours toolkit**, which can be ordered via be.Macmillan.

Volunteering

There's a lot of potential for volunteers to support patients and carers as they approach end of life, as well as carers in bereavement. More volunteering in end of life care could lead to significant improvements in patients, carers and families' experience at the end of life. However, there's no national information on what types of services already exist and where, for whom and who provides or funds them. We have commissioned the National Council for Palliative Care to scope all the existing volunteer schemes across the UK which provide practical and emotional support, including bereavement support, for patients nearing the end of their life and their carers.

This is a 2 year project and is currently in the early planning phase. The aim is to produce web-based information hub with details about community-based volunteer projects or services that are providing practical and emotional support for people in the last 12 months of life and/or their carers. This will be produced as a virtual map for the UK and will enable:

- providers and commissioners to understand availability of local projects and services
- people to access local support
- local projects and services to link
- information exchange
- ideas and inspiration for new local initiatives
- good practice to be showcased
- Macmillan to identify gaps in provision and plan future work
- links with other databases eg National End of Life Care Intelligence Network.

An evaluation tool will be developed which will enable a consistent approach to evaluating projects across the UK. It will also enable NCPC to produce an overall evaluation report with recommendations.

Management of the last days of life

It is particularly important to make sure people's needs are assessed and met as they approach the last days and hours of life. Over the last decade in the UK, palliative and end of life care providers have increasingly used integrated care pathways.

Examples are the Liverpool Care Pathway (LCP, led by the Liverpool Care Pathway team at the Marie Curie Palliative Care Institute) and the All Wales Care Pathway for the End of Life. Use of these tools helps professionals to ensure all symptoms are assessed and addressed to provide sustained high quality care.

The majority of hospitals and primary care providers use the LCP, or an adapted version of it, and undertake regular audits. Service development teams have also developed a small number of posts to support the use of the LCP. There may be a few remaining gaps in the use of these care pathways but we do not intend to do any further national or strategic work as this area is well covered by others.

Support for carers, both during a person's illness and after their death

The support of carers is vital to people approaching the end of their lives. It's a very valuable resource to health and social care services and is key to enabling people to die at home when that is their preference. There are also strong economic arguments for supporting carers of people at the end of life: carer involvement can reduce hospital re-admission rates, thereby saving both time and money[13]. It's estimated that the UK's 6 million carers save the state £119 billion per year[14].

Carers themselves, however, have their own support needs and these are often overlooked by professional services. We have **recently researched the needs of carers** of people with cancer. The findings show that:

- There are over 1 million carers of people with cancer in the UK.
- 14 % of carers are supporting someone who has a progressive cancer, and 4% are caring for someone at the end of life.
- 49% of cancer carers have at least one unmet support need.
- Only 1 in 20 (5%) of cancer carers have had a local authority carers assessment; 44% haven't heard of it.
- 26% of cancer carers surveyed have personally used or received Macmillan's services.

A recent report by Kennedy (2011)[15] explored the key concerns and support needs of older carers of people with advanced cancer. Responses showed satisfaction, in being able to provide love and care to the person diagnosed with cancer and enabling them to have a 'good' death. However, the majority of participants found caring to have been mainly challenging due to:

- miscommunication
- disorganisation
- lack of services
- lack of information and
- over-reliance on informal carers.

These factors contributed to crisis admissions to hospital; poor pain control for the patient; carers feeling overwhelmed; and residual feelings of anxiety and guilt in bereavement.

Within all four nations' strategies for palliative and end of life care, bereavement is emphasised as being important. However, there are undoubtedly gaps in services across the UK. The Palliative Care Funding Review for England acknowledges that bereavement services are important. But it does not recommend that they should be paid for via the palliative care tariff so the proposed funding position, in England at least, is not entirely clear.

As with other areas, we do have some tools and services to support carers. For example, we currently support eight bereavement schemes. In addition the Macmillan palliative care template, available in over 80% of GP practices, helps GPs identify informal carers and signposts to valuable Macmillan resources such as *Hello, and how are you?*. There are specific bereavement benefits potentially payable to surviving partners and means to help with funeral payments. We will continue to provide benefits advice, including to carers. There is also a need for estate planning support which our new financial guidance service will offer support with. We also support carers through other direct services such as the Macmillan Support Line.

Prior to that, we will have more much needed baseline information. The first national bereavement survey in England has just been launched by the Office for National Statistics on behalf of the DH[16]. It is seeking the views of 49,000 people (one in seven of all those who registered a death between November 2010 and June 2011) on the care and support they and their loved ones were given. The survey, the results of which are due in 2012, will provide information to improve key end of life care services. Coupled with our own carers research and the work on the corporate strategy route map, this should give a much clearer view of what needs to be done to improve end of life care in general and in particular support for carers. We will therefore need to do more scoping work in 2012 to determine what additional part we should play in carer support, including at end of life and through bereavement.

MacPaCC has recommended the development and evaluation of an oral history project to form an offer for volunteers and professionals to help them support bereaved families. Oral history is the collection of planned recorded interviews with individuals, collecting personal stories and opinions and is being used in palliative care. For example it has been used effectively in the Sheffield Macmillan Palliative Care Unit[17]. People who are in the last weeks and months of life are offered the opportunity to record their stories, experiences and messages. This is found to be cathartic for the dying and can be beneficial for the bereaved as digital recordings are available to them after their loved-one has died.

Throughout 2012 we will develop this as an offer to volunteers. The offer will include an equipment grant for audio/video equipment, guidance and support resources. We will also offer a series of workshops throughout 2013. The uptake and success will be evaluated in 2014.

> **'I took on the role of full time carer at home. Overnight care was a real worry to me and the offer of nursing support came too late because he deteriorated dramatically. I felt lost, and was uncertain whether to call an ambulance. As a sole carer, I felt overwhelmed by the responsibility of making that decision.'**
>
> **Mary, 51**

> **‘Just 37% of the public have written a will, 31% have registered to become an organ donor or have a donor card.’**

Raising the profile of death and dying

Raising the profile is about encouraging the general population to think about, discuss and plan for their own deaths and those of their loved ones. Recent research by **ComRes**[18] shows that 27% of the public have asked a family member about their end of life wishes and only 31% have talked to someone about their own end of life wishes. Just 37% of the public have written a will, 31% have registered to become an organ donor or have a donor card and only 8% have written down their wishes or preferences, should they become unable to make these decisions themselves (ComRes, 2012).

It is important to break the taboos in discussing and planning for end of life. These can prevent people from thinking about and therefore achieving their wishes for how they want to be cared for at the end of their lives. It can also leave people approaching end of life feeling isolated.

We are a member of the coalition for **Dying Matters**[19], led by the National Council for Palliative Care, which has the specific aim of raising the profile of death and dying. We continue to promote this work and equivalent work in the celtic nations through our website and newsletters.

Strategic commissioning

As with other parts of the cancer journey, the care and services people need as they approach the end of their life come from different sectors and settings. It's therefore vital that both the transition into end of life and the planning, contracting and monitoring of service delivery are integrated and well managed if people are to die well.

To make sure this happens we're currently scoping opportunities to work with commissioners on a system redesign project. If it goes ahead this system will pioneer whole pathway commissioning for end of life care. This work recognises the importance of the commissioning/contracting process and is intended to demonstrate that whole pathway commissioning can directly address the issue of continuity of care. Equally it will enable a shift in investment away from secondary care. It means that this has the potential to be an extremely interesting project with lessons in whole pathway commissioning which extend beyond either cancer or end of life care.

2012-2014 priorities in palliative and end of life care
Our priorities include:

- Supporting Macmillan professionals working in palliative and end of life care and upskilling the generalists in this field.
- Influencing national and local policy in all nations to promote choice, equity and affordability of care and access to 24/7 care.
- Leveraging our impact and our brand via:
  - greater use of Macmillan standards (such as Macmillan Quality Environment Mark®) in end of life care facilities and other environments where people die
  - information resources such as Advance Care Planning tool
  - offers to volunteers and professionals such as Oral History.
- Promoting health and social care integration.
- Using our learning from research and evaluation of existing services and models of care such as Midhurst.
- We are a member of the End of Life Care Alliance. We are planning a joint project with Marie Curie Cancer Care and Mencap to improve end of life care for people with learning disabilities and their carers. We will actively seek out other opportunities for partnerships with organisations working in palliative and end of life care.

Conclusion

At Macmillan we are in a good position to consolidate and extend our influence in palliative and end of life care.

It is important that we do so for several reasons, including the following:

- Dying is an important part of the cancer journey of many thousands of people. It's crucial to remember that the nature of a person's end of life and death has a profound effect not only on them but on the people they leave behind.
- We are constantly talking to and about people with cancer and people affected by cancer. It's important to be sensitive to the fact that a sizeable proportion of them are dying, will die from cancer at some point in the future and/or have lost someone close to them from cancer.
- Many people are inspired to support Macmillan because they've had meaningful personal contact with our services – most likely at end-of-life or through the loss of a loved-one. Making sure that their interaction with Macmillan at this difficult time is a positive experience will continue to inspire even more people to get involved with us.

As well as a long history in providing palliative and end of life care we already have a considerable amount of activity, people and other resources dedicated to providing, supporting and campaigning for high quality end of life care. This framework is intended to:

- marshal that existing work
- set it into a context in which we can see how it contributes to the overall improvement of end of life care
- set out a plan of action for the next 2 to 3 years
- provide an ongoing strategy within which we can channel our future work to improve the experience of end of life for people with cancer, and those they leave behind.

For further information on our palliative and end of life care programme please contact Adrienne Betteley, Programme Manager – Palliative and End of Life Care on:
abetteley@macmillan.org.uk

Appendices

Appendix 1

Examples of resources available for patients, carers and professionals (for a full directory, please visit **be.macmillan.org.uk** and **macmillan.org.uk/learnzone**). Click on links in How to access section to put MAC code into search at be.Macmillan to access these resources:

Resource	Target audience	How to access
End of life: the facts (MAC12149)	Patients and carers	**be.Macmillan**
Dying with Cancer (MAC11663)	Patients and carers	**be.Macmillan**
Palliative care, end of life care and bereavement (MAC13197)	People with learning disabilities and their carers	**be.Macmillan**
Palliative care, end of life care and bereavement (MAC13198)	Carers of people with learning disabilities	**be.Macmillan**
Hello and how are you? (MAC5767)	Carers	**be.Macmillan**
Out of hours toolkit (MAC11367_0411_CD)	Professionals	**be.Macmillan** **Learn Zone**
E-learning modules	Professionals	**Learn Zone**
Foundations in Palliative Care	Care homes and facilitators	**be.Macmillan: Facilitator pack** **be.Macmillan: Participant pack**
Was your death as good as mine? DVD (sponsored by Macmillan)	Facilitators/ educators	National End of Life Care Programme
End of Life Care in prisons – conference report (MAC13499)	Professionals working in or with prisons, commissioners and key strategic leads	**be.Macmillan**
MacPACC brochure	Professionals	**Macmillan website**
Palliative Care Master Classes	Professionals	Contact regional Macmillan Learning and Development Managers for more information.
Rich picture on people at end of life (MAC13733)	Professionals, commissioners and providers	**Available on be.Macmillan from August 2012**
Macmillan Palliative and End of Life Care Framework 2012-2014 (MAC13691)	Professionals, commissioners and providers	**be.Macmillan**
“Always There”	Report for commissioners and providers	**Contact Macmillan Policy team to find out more.**

Appendix 2

Understanding the terminology

Palliative and End of Life Care is awash with different terms and misconceptions.

We recommend adopting the following definitions (which are supported by the National Council for Palliative Care, though not necessarily developed by them) for palliative care, specialist palliative care and end of life care:

Palliative care

'Palliative care is part of supportive care. It embraces many elements of supportive care'.

It has been defined by NICE as follows: 'Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'

Palliative care aims to:

- affirm life and regard dying as a normal process
- provide relief from pain and other distressing symptoms
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients live as actively as possible until death
- offer a support system to help the family cope during the patient's illness and in their own bereavement.'

Specialist palliative care

Specialist Palliative Care Services: these services are provided by specialist multidisciplinary palliative care teams and include:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes.
- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams.
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home.

The specialist teams should include palliative medicine consultants and palliative care nurse specialists. It also includes a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

End of life care

'End of life care is care that: Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

From: **www.ncpc.org.uk**

Appendix 3

How do we fit with other funders and providers?

Macmillan's ambition is to reach and improve the lives of everyone living with cancer and inspire millions of others to do the same. One in three of us will get cancer and it's the toughest fight most of us will ever face. Anyone who's been diagnosed with cancer wants a team of people in their corner supporting them every step of the way. From the nurses and therapists helping through treatment to the campaigners improving cancer care. That's who we are.

Most of the other voluntary organisations do not focus on the earlier parts of the patient journey or survivorship, which sets us apart from them. The main organisations working in this area in the UK are set out in the table on the following pages.

Voluntary Organisation	Mission Statement	Do they deliver direct care?	Where?	Who to?	Number of members/ subscribers if appropriate
Hospices	Independent hospices have individual mission statements	Yes	Inpatient and some provide outreach and hospice at home	Cancer and majority provide to a percentage of non-malignant patients	
Help the Hospices	We want the very best care for everyone facing the end of life. We are here to support our members and other organisations as they strive to grow and improve end of life care throughout the UK and across the world.	No – provide support to hospices			189 members and 29 associate members
National Council for Palliative Care	The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition.	No – provide support to member organisations			1000 subscribers (10% individuals, 36% NHS, 36% voluntary, 18% care homes)
Macmillan Cancer Support	Cancer is the toughest fight most people will ever face. But they don't have to go through it alone. The Macmillan team is there every step of the way. We can all help. Together, we are Macmillan. We've set ourselves an impressive ambition. Our primary goal is to reach and improve the lives of everyone living with cancer.	Yes – through direct services	Information and Macmillan Support Line	Minimum 75% cancer	
Sue Ryder Care	We provide care to people living with complex long-term and end of life conditions through our homecare, hospice and residential care services.	Yes	Hospice in-patient, home care nursing now sold to private sector	All life limiting conditions	
Marie Curie Cancer Care	Everyone with cancer and other illnesses will have the high quality care and support they need at the end of their life in the place of their choice.	Yes	Hospice in-patient and home care nursing service	Min 51% cancer; max 49% non-cancer	
Scottish Partnership for Palliative Care	Our objective is to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis. With our member organisations, we contribute to national thinking and policy in relation to palliative care and promote improvements in service delivery at local level.	No – provide support to member organisations			54 members

Appendix 4

Information on MacPaCC's Work Programme

Responsibility for commissioning the individual projects moved to the Macmillan's Intelligence and Research department in 2009. Research projects were previously commissioned jointly between the Macmillan Commissioning Group, Macmillan GP Advisers and the researchers in the collaborative group. As a result five projects were funded:

- Unpicking the threads: how generalist and specialist nurses work with patients, carers and each other in the community to support Cancer survivors. Prof. Nigel King, University of Huddersfield.
- Pro-active follow-up in primary care from diagnosis of cancer: a trial of the introduction of a framework developed by service users. Professor Scott A Murray, University of Edinburgh.
- PACE study: Plans And Care Expectations. Dr Stephen Barclay, Cambridge University.
- EUReCA: Exploring, Understanding and Reducing (unplanned) Cancer Admissions. Dr Daniel Munday, University of Warwick.
- A feasibility study of a holistic needs assessment questionnaire in a supportive and palliative care service. Dr Bill Noble, University of Sheffield.

Appendix 5

Numbers of care homes across the UK

Nation	Organisation responsible for regulation and inspection of Care Homes	Number of Care Homes
England	Care Quality Commission	18,000
Northern Ireland	The Regulatory and Quality Improvement Authority	264 Nursing homes 234 Residential homes
Wales	Care and Social services Inspectorate	1,167 Care homes
Scotland	The Care Inspectorate	1,296 Care homes

References

[1] CRUK. Survival statistics for the most common cancers, five year survival rates. **http://info.cancerresearchuk.org/cancerstats/survival/latestrates/** (accessed October 2011)

[2] The definition of 'end of life' should ideally be flexible, based around an individual assessment of the patient, e.g. whether they are likely to 'recover' and how steep the trajectory towards death is likely to be. However, in order to have some sense of what that phase looks like, we are broadly using a widely accepted definition of 'the last year of life. For further definitions see appendix 2.

[3] National Institute for Clinical Excellence. Improving Supportive and Palliative Care for adults with cancer.2008.

[4] Frontier Economics: One to One support for Cancer Patients, December 2010.

[5] Macmillan Cancer Support. Always there? The impact of the end of life care strategy on 24/7 community nursing in England. 2010.

[6] Department of Health. National Cancer Patient Experience Survey (2010).

[7] FOURIE, I., (2008). Information needs and information behaviour of patients and their family members in a cancer palliative care setting: an exploratory study of an existential context from different perspectives. Information Research, 13 (4), paper 360.

[8] Macmillan estimate based on Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547; Office for National Statistics; Information Services Division (ISD) Scotland; General Register Office for Scotland; Welsh Cancer Intelligence & Surveillance Unit; Northern Ireland Cancer Registry; Northern Ireland Statistics and Research Agency.

[9] For a more detailed breakdown of deaths by cancer type and gender, see Annex B

[10] Office for National Statistics. Deaths registered in England and Wales, 2009. **http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-199137** (accessed October 2011), General Registrar Office Scotland. Cancer deaths 2009. **http://www.gro-scotland.gov.uk/statistics/theme/vital-events/general/ref-tables/2009/deaths-causes.html#table6-4** (accessed October 2011). Northern Ireland Cancer Registry. Cancer mortality 2009. **http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/AllCancers/** (accessed October 2011).

[11] Statistic taken from Macmillan February 2010 online survey of 1,019 UK adults living with cancer. Seventy-three percent of people with cancer said they would prefer to die at home if all their concerns about dying at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed.

[12] For the numbers of homes across the UK, see Appendix 5.

[13] Princess Royal Trust for Carers: Out of Hospital (July 2010)

[14] Carers UK: Valuing Carers (2011)

[15] Kennedy S et al (2011) Macmillan Cancer Support & University of Nottingham Exploring the key concerns and support needs of older carers of people with advanced cancer

[16] The survey is being funded by the DH as part of the End of Life Care Strategy. Link for more information: **http://www.endoflifecareforadults.nhs.uk/news/all/launch-of-national-bereavement-survey**

[17] Winslow M, Smith S, Hitchlock K, Noble B. Four year report Oral History and Photography in Supportive and Palliative Care. 2011

[18] ComRes (2012) Brits paying price for refusal to talk about dying. **http://www.dyingmatters.org/page/brits-paying-price-refusal-talk-about-dying** (accessed May 2012)

[19] The Department of Health and the National Council for Palliative Care have set up Dying Matters, a coalition that aims to raise the profile of end of life care and to change attitudes to death and dying in society. The coalition has over 15,000 members, including some from the Celtic Nations. Each nation also has a group working on their national awareness-raising campaign.

Cancer is the toughest fight most people will ever face. But they don't have to go through it alone. The Macmillan team is there every step of the way.

We are the nurses, doctors and therapists helping people through treatment. The experts on the end of the phone. The advisers telling people which benefits they're entitled to. The volunteers giving a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions people affected by cancer might have through our free Macmillan Support Line on **0808 808 00 00** Monday to Friday, 9am to 8pm.

Alternatively, visit **macmillan.org.uk**
Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.

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