

# **PACE Steps to Success Programme**

**Steps towards achieving high quality palliative  
care in your care home**

## **Information Pack**

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**Date of publication**

**31<sup>st</sup> January 2019**



## Acknowledgements

### Funding

The research leading to these results received funding from the European Union's Seventh Framework Programme under grant agreement number 60311 (PACE: Comparing the effectiveness of **P**alliative **C**are for **E**lderly people in long-term care facilities in Europe, project conducted 2014-2019). We thank all care homes and their staff for participating in this project, as well as all general practitioners, physicians, and relatives.

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## Foreword

There is little doubt that as our population across Europe ages in the coming years, the care of older people living with the consequences of chronic, debilitating and life-limiting illness will have a significant impact on our health services and the way in which we will need to deliver care. The role of staff in care homes will be critical to the delivery of optimal older person care and so we need to be prepared for the changes that this will bring.

Despite a shift in thinking which places palliative care across the trajectory of chronic illness, we still sometimes see palliative care in terms of the last days of life, what was once called 'terminal care' with a focus on death and dying. Palliative care today is so much more than that. As a vehicle for good care at end-of-life, it is about how we live until we die and what we can do to enhance the quality of that living until our life ends, from whatever cause. Still, the skills to manage care at end-of-life are part of the repertoire needed by staff to care for older persons, skills that can always be enhanced and updated.

The PACE project has provided a platform on which we can build better and more cohesive palliative and end-of-life care for older people living in care homes. This document highlights a number of critical issues to the success of good palliative care delivery. The first is planning. The step-wise approach promoted here focuses on a need for a co-ordinated partnership of care – one that involves healthcare workers within and external to your organisation alongside the resident, and their family. The second is documentation so that everyone understands what is happening in a clear and concise way that makes the planning and communication of changing goals of care, easier and more understandable. The third is knowledge about the illness, the person, the system and how that is applied to make the outcome of life's end as comfortable and compassionate as it can be. Overall, the PACE Six Steps programme and the stages of learning provided in this document reminds us that palliative and end-of-life care is always about doing the right thing at the right time for the right reason. To follow the guidance offered here will provide the structure within which you can offer excellence in care at end-of-life in your care home. Careful attention to each step leads to the opportunity to enhance care and provide evidence to those to whom we are responsible for all our actions; not only the regulatory bodies but those who we care for.

The European Association for Palliative Care has been delighted to partner with our European colleagues involved in the PACE project and to see this important work evolve and develop over time. We are sure that the end product of this work will assist in establishing the highest possible standards of care for older people living in care homes with palliative and end-of-life care needs in Europe, adaptable to the specific needs of each country and responsive to the changing trajectory of need to expand older person palliative care. Implementing this programme of work at local level in your care home adds to the wider focus on older people and for that, it is a welcome and essential tool for improving practice.

As President of the EAPC, I extend my thanks to the PACE project team and wish you, as practitioners and managers, every success with its implementation and evaluation to make sure we will always seek better palliative care for our older citizens.

Philip Larkin

President, European Association for Palliative Care

## **BACKGROUND TO THE PACE PROJECT – Comparing the effectiveness of Palliative Care for older people in long-term care facilities in Europe.**

The PACE consortium consisting of 8 research institutes, spanning 6 European countries, and 4 European organizations responsible for impact and dissemination, has performed three studies between 2014 and 2019. Firstly, PACE mapped palliative care systems in long-term care facilities (LTCFs) such as care or nursing homes across 29 countries in Europe<sup>1,2</sup>. There is considerable variation in the types and funding mechanisms of LTCFs across Europe, in the populations living in these settings, and in the extent to which palliative care is developed or organised within LTCFs. In many countries, palliative care is not well integrated in long-term care.

Secondly, the consortium performed a large-scale representative study to examine quality of dying and palliative care in LTCFs in different EU countries in 2015<sup>3</sup>. PACE evaluated the end-of-life care provided to 1,707 deceased residents of 322 LTCFs in Belgium, the Netherlands, England, Finland, Poland and Italy, by asking care staff and relatives of the identified residents to fill in structured questionnaires. Additionally, all the nurses and care assistants of each facility were asked to fill in a questionnaire evaluating their knowledge and attitudes regarding palliative care. Results of this study suggest room for improvement in the quality of dying and quality of end-of-life care in LTCFs in all countries, even in those with high levels of palliative care development in LTCFs such as Belgium, the Netherlands, or England<sup>4</sup>. The knowledge of nurses and care assistants concerning basic palliative care issues varies considerably between countries and can be improved in all countries<sup>5</sup>.

Lastly, PACE conducted a cluster randomised controlled trial in 2016-17 across 7 countries (Belgium, the Netherlands, England, Finland, Poland, Italy, and Switzerland) to study the impact of the 'PACE Steps to Success' intervention programme, which aims to integrate palliative care in LTCFs<sup>6</sup>. The results of the effectiveness study will be published in 2019. An in-depth process evaluation running in parallel, showed that the implementation of the different steps in the PACE Programme varied between settings, and identified important barriers and facilitators to take into account when implementing palliative care in these complex settings. The results were used to refine the original PACE Steps to Success Programme, resulting in the programme Information Pack presented here. We recommend implementation of the PACE Steps to Success Programme, in a flexible way in terms of timing and order, adapted to the facility's context, with the help of well-trained facilitators, and together with close and ongoing evaluation and monitoring. For people with complex palliative care problems or end-of-life symptoms, specialized palliative care services should also be easily accessible to long-term care facilities in all countries.

The programme will be made available online and is openly accessible in the different languages of countries involved in the PACE trial. The PACE consortium hopes that PACE results will be used to further optimize the delivery of palliative care to all older EU citizens in the future.

## Selective list of PACE publications

1. Froggatt K, Payne S, Morbey H, Edwards M, Finne-Soveri H, Gambassi G, Pasman HR, Szczerbinska K, Van den Block L, on behalf of PACE. *Palliative Care Development in European Care Homes and Nursing Homes: Application of a Typology of Implementation*. Journal of the American Medical Directors Association, 2017. **18** (6): p. 550.e7-550.e14. doi: 10.1016/j.jamda.2017.02.016
2. Froggatt K, Arrue B, Adwards M, Finne-Soveri H, Morbey H, Payne S, Szczerbinska K, Van Den Noortgate N, Van den Block L. *Palliative care systems and current practices in long term care facilities in Europe*. Report of the EAPC Taskforce, March 2017.
3. Van den Block L, Smets T, van Dop N, Adang E, Andreasen P, Collingridge Moore D, Engels Y, Finne-Soveri H, Froggatt K, Gambassi G, Kijowska V, Onwuteaka-Philipsen B, Pasman HR, Payne S, Piers R, Szczerbińska K, Ten Koppel M, Van Den Noortgate N, van der Steen JT, Vernooij-Dassen M, Deliëns L; PACE. *Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries*. Journal of the American Medical Directors Association, 2016. **17** (6): p. 566.e1-566.e7. doi.org/10.1016/j.jamda.2016.03.008
4. Pivodic L, Smets T, Van Den Noortgate N, Onwuteaka-Philipsen BD, Engels Y, Szczerbińska K, Finne-Soveri H, Froggatt K, Gambassi G, Deliëns L, Van den Block L, on behalf of PACE. *Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study*. Palliative Medicine, 2018. **32** (10): p. 1584–1595. doi: 10.1177/0269216318800610
5. Smets T, Pivodic L, Piers R, Pasman HRW, Engels Y, Szczerbińska K, Kylänen M, Gambassi G, Payne S, Deliëns L, Van den Block L, on behalf of PACE. *The palliative care knowledge of nursing home staff: The EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries*. Palliative Medicine, 2018 **32** (9): p. 1487-1497. doi: 10.1177/0269216318785295
6. Smets T, Onwuteaka-Philipsen BBD, Miranda R, Pivodic L, Tanghe M, van Hout H, Pasman RHRW, Oosterveld-Vlug M, Piers R, Van Den Noortgate N, Wichmann AB, Engels Y, Vernooij-Dassen M, Hockley J, Froggatt K, Payne S, Szczerbińska K, Kylänen M, Leppäaho S, Barańska I, Gambassi G, Pautex S, Bassal C, Deliëns L, Van den Block L; PACE trial group. *Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the ‘PACE Steps to Success’ intervention in seven countries*. BMC Palliative Care, 2018. **17** (1): p. 47. doi: 10.1186/s12904-018-0297-1

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## INTRODUCTION

The PACE Steps to Success Programme is an educational and development initiative for staff designed to improve palliative care in care and nursing homes. This document has been prepared for care home managers and facilitators. It aims to help you understand what the PACE Steps to Success Programme is and how you can use it to improve the care you provide. The PACE Steps to Success Programme provides you with information and resources to help optimise quality of life for all residents and to support their families, using an approach called 'palliative care'. **In the rest of the document, we will use the term 'care home' to refer to all types of care homes, nursing homes and long term care facilities.**

There has been a rise in the number of frail older adults that require additional support and long-term care in a care home. With longer life expectancy, most frail older adults are living with advanced progressive, incurable diseases. The quality of their remaining life is important.

The PACE Steps to Success Programme was developed and tested as part of an international study (2014-2019), funded by the European Commission 7<sup>th</sup> Framework Programme, which aimed to improve palliative care for older people in care homes (for more information see [www.eupace.eu](http://www.eupace.eu)). It involved seven European countries, as listed in the Background. The outline of the PACE Steps to Success Programme was adapted from the Route to Success training, which was designed by the End of Life Care Programme in England to help staff caring for frail older adults in care homes to deliver high quality palliative and end of life care [1]. It drew upon two other programmes, namely: the Gold Standards Framework for Care Homes [2] and the Macmillan Foundations in Palliative Care [3].

## Aim of the PACE Steps to Success Programme

The aim of the programme is to provide care home managers and facilitators with a guide to support the development of a palliative care culture in your care home. This means training all staff to deliver basic general (not specialist) palliative care. By introducing the programme, you will enable all staff to improve end of life care and increase their knowledge about palliative care in order that residents can live and die well in the care home. A key part of introducing this programme in your care home is about creating a shared vision amongst care home managers and staff to improve the care given to all residents from admission to the end of life.

This Information Pack will assist you to introduce the programme. We recommend that two or three key individuals are identified in the care home to lead the introduction of the programme and help staff to understand each Step of the PACE Steps to Success Programme. A facilitator could be a nurse, social worker or doctor with experience of working in care homes, and ideally, they will have some knowledge of palliative care. This person is a member of staff in the care home or could be an external person. We suggest that you plan a regular dedicated time for staff to develop their knowledge about each Step. Each Step has learning objectives, information to increase knowledge and skills, and exercises to help implementation. We have structured each step to provide the following information:

Background for the facilitators

Barriers and solutions

Training session:

- Learning objectives
- Preparation
- Training and exercises
- An example of a completed tool

Resources

During the PACE clinical trial we used both **external and internal facilitators**. Prior to the trial, we identified 1-3 people who worked in each country to deliver training on the PACE Steps to Success programme. They were called 'country trainers' and were trained for a week to learn about the overall programme. Most of them had professional qualifications in medicine, nursing, counselling or social work, and they already had experience of palliative care and/or care homes. Within the PACE clinical trial, care homes were randomised to receive either the PACE Steps to Success programme or to continue with usual care. In those care homes who

were randomised to implement the PACE Steps to Success programme, care home managers identified two to three facilitators (called ‘coordinators’ in the trial) who were normally qualified nurses, although in some cases, they were experienced care workers. These people were members of the care home staff. They were trained by the ‘country trainers’ on the PACE Steps to Success programme before it started. During the implementation of the programme during the trial, the country trainers visited each care home every month to teach the next step to all staff. The facilitators who worked in the care home were then available to support staff to introduce the Step and ensure that it was embedded in practice over the following month. We found it helpful to have two to three facilitators in each care home to allow for periods of holiday leave, sickness or staff turnover. The skills and competencies necessary for a good facilitator include:

- **Previous health care experience** in order to understand the dying process.
- **Palliative care experience** in order to speak openly about death and dying.
- **Ability to train and empower care home staff** and to be a role model.
- **Understanding of the care home context**, especially the nature of chronic disease.
- **Ability to collaborate** with care home staff and external health care professionals.
- **Motivation** to make change and determination to resolve any challenges.

We recommend that either external or internal facilitators are used to implement the PACE Steps to Success programme. The programme involves more than a checklist approach so understanding each Step is important to ensure safe and effective practice. It is not sufficient to start using the tools without helping staff to understand the reason for each Step.

## **How can the PACE Steps to Success Programme be delivered and supported?**

We suggest the PACE Steps to Success Programme is introduced in three phases over 12 months, using the order of Steps presented here. However, you can change the order of the Steps and increase the time taken to learn about each Step, if necessary.

The PACE Steps to Success Programme is normally delivered over 12 months in three phases:

- **‘Getting ready’**
- **‘Introducing the programme’**
- **‘Keeping the programme going’**

The first two months involve **‘Getting ready’** to start the programme, raising awareness amongst staff, residents, families and health care professionals who work outside your care home. During the **‘Introducing the programme’** part, the six Steps are introduced sequentially one Step each month. Each Step helps to keep the momentum going within the care home. After the sixth and last Step, there is a final period of four months to embed the PACE Steps

to Success Programme in practice. This is the '**Keeping the programme going**' stage. We recommend this time scale but there can be some flexibility, if you need longer to embed each Step, or for a Step that seems more challenging.

***What is the role of care home staff?***

All staff need time to understand the six Steps and to make changes to practice. The support of colleagues helps them to use the new tools and charts in practice. The programme is about developing a strong team to help enhance a palliative care approach.

***What is the role of the doctors associated with your care home?***

The doctor plays an important role in the quality of life of frail older people. The PACE Steps to Success Programme provides a structure that aims to enable better communication about the palliative care needs of residents and their families. The programme works well when the doctor can attend the monthly multi-disciplinary palliative care review meetings in your care home where the palliative care needs of residents are discussed. These meetings should be well organised, short and efficient. It is important to raise awareness with the doctors overseeing the care of residents in your care home as soon as possible to try to encourage their participation and support with the programme.

***What is the role of the care home manager?***

The role of the care home manager is to support the implementation of the programme. All staff will require time to learn about each of the Steps in dedicated training time. In addition, facilitators may require time to learn more about palliative care. If the facilitators work within the care home, they will require some dedicated time to implement the programme. Managers should consider how to motivate staff, perhaps using incentives, to implement the changes. New documentation needs to be introduced, such as the monthly palliative care registers and the PACE tools, if your care home does not already use them. If you already use similar tools, they need to be integrated into the Steps. The care home manager and the doctor can decide on the best time to schedule the monthly multi-disciplinary palliative care review meetings.

## What is Palliative Care?

Palliative care aims to promote good quality of life and symptom management for people living with life-limiting conditions, including frail older people. In some countries, palliative care is closely associated with care for people with cancer but we now know that it can benefit people with other illnesses, especially older people in care homes [4].

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**Palliative care** is the active, total care of those whose disease is not responsive to curative treatment. **Palliative care** takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms.

**Palliative care** is interdisciplinary in its approach and encompasses the care of the patient and their family. **Palliative care** should be available in any location: hospital, hospice, care home and community.

**Palliative care** affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

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## GETTING READY TO START

### Objectives during the 'Getting ready' stage (2 months)

- Identification of two to three key facilitators. We recommend a ratio of at least one facilitator per 30 beds. It is usually the role of the care home manager to identify these people.

Key facilitators and the care home manager need to:

- Read the PACE Steps to Success programme document and discuss it with staff.
- Be able to implement each of the six Steps in PACE Steps to Success programme.
- Review and integrate the tools associated with the PACE Steps to Success programme, using electronic systems if they are available.
- Discuss the implications of the programme and consider how to make changes, clarify expectations of what is expected of all staff with respect to the tools.
- Consider what resources are needed to implement the PACE Steps to Success programme.
- Raise awareness in the care home about the programme by having meetings with the day and night staff (nurses, care staff, cooks, cleaners, gardeners, volunteers).
- Send out invitations to relevant doctors and other external health and social care professionals to attend a meeting to raise awareness about the PACE Steps to Success programme.
- Invite residents and families to a meeting to discuss the PACE Steps to Success programme. During the meeting with residents and their families explain the goals of the programme, stressing the opportunities and advantages it offers. Explain that all residents will be invited to discuss their current and future care preferences, regardless of their actual health status.
- Set dates for training and communicate them to all staff.

## Background for the facilitator

We recommend that two months is taken for 'getting ready to start' the programme. During this time, it is important to ensure that staff have time to familiarise themselves with the PACE Steps to Success programme and resources. Staff may have questions or concerns about how to manage changes and how their roles might differ. It might be helpful to talk about processes of change. It is also important to improve communication skills, understand the impact of loss, grief and bereavement, and the sensitivity of talking about death and dying.

This is also a good time to raise awareness and enthusiasm about the programme amongst staff, residents, families, and other health and social care professionals, as well as volunteers, who are closely associated with your care home. It is important to prepare residents and their families so they are aware of potential changes. You can explain what palliative care is and how it can benefit them. You can offer opportunities to listen compassionately to any concerns, such as during family visiting times.

During the 'getting ready' phase, the facilitators need to:

- Understand their role in helping to introduce the programme.
- Have a good understanding of the PACE Steps to Success programme and its tools.
- Take responsibility for the preparations needed before starting the programme, and support and encourage other colleagues.
- Appreciate the diversity of skills amongst colleagues and encourage others to help you. Having the support and encouragement of the care home manager and fellow colleagues will help foster a cohesive team approach to embed change.

Potential barriers during getting ready	Solutions
It is too difficult to ask residents and their families to attend a meeting	It is important that everyone has the opportunity to hear about the PACE Steps to Success programme. You may be surprised how interested families and residents are. However, it is likely that those who attend will mostly be relatives of residents. Relatives want their family member (and themselves) to be well cared for - especially towards the end of life.
Some staff are resistant to change	Work with those staff who are willing and understand the importance of the PACE Steps to Success programme. Often, the others will then follow.



## Leaving Home Exercise

This is a practical exercise for staff, which is designed to help them understand how people experience major changes that lead to losses in their life. It helps people to think more about what it may be like to move out of a domestic home into a care home. During a staff meeting, work through each part of the exercise.

### LEAVING HOME 1

The area that you live in has had a period of heavy and ongoing rainfall over the past few days. You have heard on the radio and seen an alert on Facebook that the area you live in is at risk of further flooding. As a safety measure, the local police are asking residents to evacuate their houses. You have just one hour to gather three items to take with you. You have been informed that you will be accommodated at the local sports centre. Any pets you have will be looked after at a nearby animal shelter.

Which three items will you take?

What are your concerns/reactions?

### LEAVING HOME 2

You have spent the night at the sports centre. In the morning, you are told that all the houses on your street have been damaged by the floodwater and you are unable to return to your house. You will be moved to a communal living centre in the next town while a decision is made about temporary housing. You will have your own room but you will be sharing all facilities with 30 other people. Meals and laundry facilities are provided for a set monthly fee.

You arrive at the centre. It is attractive and warm. The people there are quite friendly but you do not know anyone.

What are your thoughts and feelings?

## Introducing the PACE Steps to Success programme

The PACE Steps to Success programme is introduced one Step a month over a six-month period following a two-month 'getting ready' phase, if necessary you can take longer. We use the word 'tool' to refer to assessment measures, forms and charts that help put each of the Steps into practice. If your care home already uses a similar tool, you can continue to use it, or merge the two documents, whatever fits best. If you do not currently use any structured tools, we suggest that you introduce the ones described in this Information Pack and in the Tools Annex. You can adapt them to the special requirements of your care home if necessary.

### PACE Steps to Success Programme: Steps content and tools



<b>Getting ready stage (2 months)</b>	Month 1	Raising awareness <ul style="list-style-type: none"> <li>• Preparing residents and families</li> <li>• Talking with staff about change</li> <li>• Talking with professionals outside the care home</li> </ul>	
	Month 2		
<b>Six monthly Steps stage (6 months)</b>	Month 3	STEP 1	Communication Training for care home staff in relation to 'Looking Thinking Ahead' document
	Month 4	STEP 2	Training: Dying trajectories and 'Mapping Changes in Resident's Condition' tool
	Month 5	STEP 3	Compile Palliative Care Register + commence MONTHLY multi-disciplinary palliative care review meetings
	Month 6	STEP 4	Training: Symptom assessment and management of PAIN and use of tools
	Month 7	STEP 5	Training sessions for LAST DAYS OF LIFE documentation + process of dying. ALL staff to be trained + doctors/external team members where possible
	Month 8	STEP 6	Commence MONTHLY group reflective debriefing sessions and complete death audit data sheet for residents who have died
<b>Keeping it going stage (4 months)</b>	Month 9	Consolidation of all tools/actions implemented and the continuation of: <ul style="list-style-type: none"> <li>• Monthly multi-disciplinary palliative care review meetings</li> <li>• Monthly reflective de-briefing sessions</li> </ul>	Monthly training to continue depending on level of palliative care expertise in each care home (for example: Communication; Symptom Control; Dementia)
	Month 10		
	Month 11		
	Month 12		

## Overview of tools used in PACE Steps to Success Programme

Step of programme	Tool
Step 1	'Looking and Thinking Ahead' document: to record discussions around current and future care, including at the end of life
Step 2	'Mapping Changes in Resident's Condition' chart
Step 3	Palliative Care Register Summary Sheet
Step 4	Care Home Pain Assessment and Management Tool encompassing assessments for people with and without dementia
Step 5	Management in the Last Days of Life checklist + scenario for teaching 'Care during the last days of life'
Step 6	Reflective Debriefing Tool for staff Death Audit chart



## **Step 1: Discussions towards the end of life**

Discussions with residents about what living well means to them, and what their future preferences for future care are, is the first step. It also involves exploring their thoughts around any preferences or wishes they might have towards the last few months, weeks and days of their life. In some countries, this process is called '**advance care planning**' and choices can be formalised in **advance directives**.

### **Objectives for staff to undertake Step 1**

- To gain confidence in discussing current care and planning for future care, including towards the end of life, with residents in the care home.
- To undertake discussions with residents and/or families, as well as encouraging other nurses and care assistants to do so too, in relation to preferences and wishes for care towards the end of life.
- To ensure that every resident and their family have been offered the opportunity to talk about their preferences and wishes for current and future care, including care towards the end of life.
- To be familiar with what advance care planning means in your country and the associated documentation used in the care home for recording discussions.
- To encourage staff in the care home to be present at advance care planning discussions with the residents they care for.
- To formalise the recording of advanced care directives and ensure that staff are aware of whom to inform about their existence.

Many frail older adults in a care home have often already thought about the future, including their eventual death. Some people might have already prepared ahead financially but often lack the opportunity to discuss their preferences and wishes about their current and future care towards the end of life.

Sometimes a change in the health of a friend or another resident's death might prompt discussions about future care. At this time, the resident might try to start discussions about his or her own care towards the end of life. These conversations are '**opportunistic**' moments for all care staff to be willing to talk with residents. Often these conversations are about a willingness to listen to a person's concerns rather than providing answers.

**Planned discussions** about future care are usually undertaken with a doctor or by nurses, and in some countries, by experienced care assistants. Discussions should be about living well during the remaining months or year(s), not just about the last few days of life. Some residents may not wish to talk about the future, and their choice should be respected. It is not a requirement that all residents have these discussions, but it is important to offer everyone an opportunity to do this. It may also be helpful to involve families in such discussions.

Many care home staff do not feel comfortable talking about death and dying. Training and support are important to increase confidence. Also, consider undertaking some additional communication skills training for all staff at this stage.

## **ACTIONS**

- Have discussions with residents about their preferences for current and future care. The tool provides a structure on how to undertake and record discussions with residents about current and future care.

## **TOOLS**

- 'Looking and Thinking Ahead' document: preferences and wishes about current and future care.

## Background for the facilitator

Discussions about people's preferences and wishes for current and future care towards the end of life are called 'advance care planning'. These discussions are rarely a single event but usually involve a series of on-going discussions between residents, their family and staff.

### Helpful points about discussions on current and future care

- Discussions can occur **opportunistically** when a resident brings up the subject for some reason i.e. if another resident has recently died. All staff need to know how to manage such an opportunity and not to simply dismiss it. All staff should be attentive to requests from residents and should know how, and to whom, to report them.
- Residents can start **opportunistic** discussions when they trust a member of staff enough to discuss it. It often just requires the confidence to be present, attentive and to simply sit and listen.
- Discussions can be **planned for with**:
  - New residents to the care home: this should be done within 4-6 weeks following admission
  - Residents already in the care home: this should be during their next formal review of care.
- **A nurse or a doctor should undertake planned discussions** with the resident and their family.
- It is important to offer the opportunity for these discussions **early** especially if it is known that a resident will lose their mental capacity to say what they would like to happen in the future, for example with cognitive impairment or following a diagnosis of dementia.

These discussions need to be documented. Further follow up discussions need to be updated on the forms used.

- If a resident and their family do not want to talk about the future, then that is their right but it is important to document that an opportunity for a discussion has been offered and refused.
- The contents of the form should guide a sensitive conversation with the resident and their family, and not be used as a tick-box.

### Two main aspects of advance care planning

- Formalising what a resident and family **do** want to happen which are statements about a person's preferences and wishes (i.e. where they would like to be cared for in the last days of life) which can be changed and re-discussed.
- Formalising what a resident and family **does not** want to happen. In some countries, an Advance Decision to Refuse Treatment is legally binding.

## Barriers and solutions

Potential barriers to discussing current and future care	Solutions
Frail older people do not want to be reminded they are near the end of life by talking about the possible care they would like to receive	Most frail older people living in care homes know that their condition is deteriorating – because their body tells them so. We are not reminding them. Many residents think about death and dying quite a lot.
Staff feel they do not know what to say or what words to use when suddenly a resident starts a conversation about dying	Remember that simply ‘listening’ to a resident is an important part of supporting a resident.
Staff feel that they might get into trouble if they say the wrong thing or the resident starts crying	If a resident becomes tearful then their emotion needs to be expressed. The resident generally opens up to a member of staff because they trust them. Care staff and nurses must always report a discussion about future or end-of-life care to the person in charge.
It feels awkward to talk about end of life care issues to residents and/or families	While many people feel anxious talking about issues to do with future and the end of life, residents have often begun the process through addressing their financial affairs, e.g. writing a will. These discussions are a further step in this process to talk about preferences and wishes for care in the future.
I do not know how to start such a discussion	With help from the PACE Steps to Success Programme you will gain in confidence. You may need to learn more about communication skills. Good nurses and care workers earn the respect of residents and, when they do, residents may want to ask them difficult questions. It is important not to shy away from replying but keep the discussion going by replying with an ‘open’ question. <b>It is not appropriate to use the ‘Looking and Thinking Ahead’ document as just a checklist.</b>
Residents may be concerned that these discussions indicate that they will die soon.	<b>Reassure all residents that these discussions are a routine part of planning care goals for everyone</b> , and it does not indicate that they are dying.



## Training session: Discussions about current and future care

### Learning objectives:

- To learn the skills of 'active listening' when involved in discussions with frail older people.
- To know how to respond to a difficult question from a care home resident.
- To understand what is behind strong emotions and 'outbursts' in people who are faced with a family member who is ill.

### Preparation

- Make sure that a 'flip chart' or pen/paper is available
- Bring a 'Thinking and Looking Ahead' document for each staff member attending

### Training and exercises

#### 'Back to Back'

Ask staff to get into pairs and sit back to back with another member of staff. Ask one person in each of the pairs to talk about a recent event, for example a holiday, birthday, day out etc. for a couple of minutes whilst the other person listens.

After a couple of minutes get the group back together and ask:

Q: How did it feel for the people doing the talking?

Q: How was the experience for the people that were listening?

### Key learning points

- To understand the importance of the various ways in which we communicate.
- To highlight the challenges that might make communication difficult.
- To highlight skills to try and improve and enhance communication.

### General theory about communication

- Ask the group if they know what goes into communicating well with people. What makes speaking a good experience?
- Get the group to write them down and then feedback their answers onto the flip chart, adding to the flip chart any that haven't been mentioned.

**Answer:** being listened to; feeling the other person understands and is interested; being able to express feelings; when the other person contributes to the conversation; when people ask a question within the conversation; being asked to explain more about something; having people clarify what you are trying to say; being non-judgemental.

### **Learning points**

Active listening, clarifying a situation, and reflecting back, are all valuable skills that can help open up conversations about end of life care.

### **What is palliative care?**

Ask the group if there is anyone in the care home that they consider being in a 'palliative' stage of their illness. Let them discuss what they feel about the residents. Have any residents mentioned to a member of staff that they might not have long to live or be dying? If so, how did the member of staff respond?

It can be tempting to try to avoid these discussions in case they do 'more harm than good' and upset a resident. However, for a resident crying may be an important release for them. Interestingly, many residents are quite resilient and in fact often know that they are at the end of life without being told explicitly. If a resident starts to talk about dying, it is because they have come to trust that person and want to open up to them. If we deny them this opportunity, they may never talk about it to anyone else.

Watch Resource Video One: What is Palliative Care?

### **Active Listening**

With **active listening**, our body language is very important. This includes:

- Eye contact.
- Body position (leaning forward, attentive facial expression, sitting on a level with the resident or lower than them in an open posture).
- Being in a place where we are not distracted by noise, sound other people.

Find somewhere quiet; remove distractions; concentrate and make mental summaries; respect and value the other person; do not judge but try to see the other person's perspective.

- **Ask the group to think what they would say if a resident said, 'I think I might be dying?'**

**Learning points:** When faced with a difficult question it is important to **listen** and use skills to help, such as:

- **Repeating back a question**
- Response: 'What makes you think that you are dying?'

- **Paraphrasing** is a way of expressing meaning using different words, to help achieve greater clarity.
- Therefore, a response to the question using **paraphrasing** could be:
- Response: ‘So you think that you might be dying’

**Ask the group why these skills might be helpful**

### **Learning points**

- Gives time for the member of staff to compose themselves.
- Encourages the resident to continue talking to you.
- It shows that you are listening.

### **Coping with Strong Emotions**

Learning to cope with strong emotions in people involves a mixture of skills. Within the context of death and dying, some family members feel angry and show strong emotions. In these situations, it can be helpful to acknowledge and validate their feelings, listen and be non-judgemental:

Response: ‘I can see and understand that you are angry/upset/shocked/devastated...’

It is best to have these conversations in a ‘safe place’ somewhere private for example in the manager’s office. Be human - emotions are a normal part of loss and expressing them helps to accept their own feelings of helplessness. Try to establish a relationship of trust and most importantly - **LISTEN**

### **Discussions about current and future care**

Discussions involving advance care planning are usually conducted by a doctor or qualified nurse, for example:

- Discussions about preferences and wishes for current and future care including the end of life.
- Discussions about end of life health care choices.
- Decisions regarding cardio-pulmonary resuscitation.

### **Discussions about end of life: Preferences and wishes**

**Planned** – These discussions are offered to all new residents and to all residents when starting the PACE programme, regardless of their actual health status. The discussions should occur within 4-6 weeks following admission to the care home for new residents. The formal care planning review can be a good time to include discussions about the resident’s current and future preferences and wishes at the end of life. Frail older people are often not afraid of death, but get little opportunity to talk about it. When asked they often know exactly what they want.

**Opportunistic** – These discussions tend to happen when least expected, therefore it is important that all staff are confident in dealing with such an opportunity. The resident will most likely have opened up to you because they respect and trust you and have built up a good rapport. The important thing is to allow the residents to speak for themselves and offer them a formal appointment time as well.

### **Planned Discussions using the ‘Looking and Thinking Ahead’ document**

The ‘Looking and Thinking Ahead’ document offers a way to structure a discussion about current and future care (including at the end of life). The questions in the document are not difficult to ask. An experienced care assistant who knows both the resident and the family well can undertake such a discussion but will need to refer any queries about health or clinical issues to the doctor or nurse. **The tool is not a checklist.** It helps to guide a sensitive and open discussion.

Hand out the ‘Looking and Thinking Ahead’ tool to each member of staff present.

- Ask everyone to read the first page through – and check if there are any questions.

### **Exercise – Looking and Thinking Ahead**

- Ask the staff to get into pairs and read the questions on the second page of the ‘Looking and Thinking Ahead’ tool.
- Get them to take a few minutes to think about how they would ask the questions on the ‘Looking and Thinking Ahead’ tool. Emphasise that it is a guide not a questionnaire.
- Get each of the pairs to take it in turns to practice, asking the questions and answering them. After 5 minutes get them to swap over so that they both have the opportunity to ask and answer questions.
- After 10 minutes bring the group back together and ask them to feedback their thoughts on how they found the experience.

### **Key learning points**

- Staff familiarise themselves with the questions on the ‘Looking and Thinking Ahead’ tool.
- Allowing staff to practice asking and answering the questions on the ‘Looking and Thinking ahead’ tool can help highlight individuality. This exercise can demonstrate how our choices differ, which is no different to that of residents living in care homes.

By the end of the year, all residents in the care home will have an opportunity to speak to staff about their preferences and wishes towards the end of life. Discussions are best when a rapport has been established between the resident and nurse or senior care worker.

Discussing a resident's preferences and wishes for current and future care therefore generally takes place a couple of months after admission. In most care homes, care is fully reviewed at six months – this can also be a good time to add 'end of life care wishes' to the other more general care needs discussed at this time.

Towards the end of the teaching session:

- get staff to raise any concerns they have about having these discussions,
- ask them which resident/s they think should be invited to have a 'Looking and Thinking Ahead' discussion over the next month.

Finally, ask staff to consider

- Those residents who are deteriorating and have not yet had the opportunity to discuss their preferences and wishes.
- Those who already have a decision regarding cardiopulmonary resuscitation.
- Planning a care planning review meeting and adding questions to elicit views about current and future care into the review meeting of those residents that are currently stable.
- All new residents admitted to the care home should have the opportunity for a planned discussion within 4-6 weeks following admission.

## Resources

**Mental capacity** refers to the capacity of an individual to make decisions. It should not be assumed that a person lacks capacity solely based on a diagnosis of dementia. The mental capacity of an individual may vary depending on different factors such as the environment, level of education, personality, health, impairments etc. Lack of capacity may not be a permanent condition. The capacity of a person may change over time, this includes in long-term, but also the short term (e.g. within a single day, some people may have more difficulties for making decision at a particular time of the day). In addition, it is important to consider that capacity is not an "all or nothing" concept. In some cases, a resident may be able to make a decision but only with appropriate support. Some people may lack capacity to make some decisions but not others. The assessment of capacity should be time and task-specific. Assessing the capacity of a person is a complex task. Different countries have different laws addressing how to assess capacity. Supporting people with dementia to express preferences, needs and wishes requires time, effort and appropriate skills.

### **Further information for the UK, if you work elsewhere check the local requirements**

In the United Kingdom, different laws exist in England and Wales (Mental Capacity Law 2005), Northern Ireland (Mental Capacity Act Northern Ireland 2016) and Scotland (Adults with Incapacity (Scotland) Act 2000).

- Mental Capacity Act Code of Practice (2007) published by The Stationery Office on behalf of the Department for Constitutional Affairs. Available at: [www.gov.uk/government/publications/mental-capacity-act-code-of-practice](http://www.gov.uk/government/publications/mental-capacity-act-code-of-practice)
- Chapman S (2008) The Mental Capacity Act in Practice: Guidance for End of Life Care. London; National Council for Palliative Care.
- Social Care Institute for Excellence (2015) Mental Capacity Act (MCA) Directory [www.scie.org.uk/mca-directory/making-decisions/](http://www.scie.org.uk/mca-directory/making-decisions/)
- Regnard C (2012) Deciding Right; An integrated approach to making care decisions in advance with children, young people and adults.
- End of Life Care Programme (2008) Advance Care Planning: A Guide for Health and Social Care Staff. [www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf](http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf)

Resource Video One: What is Palliative Care?

## Looking and Thinking Ahead

A document to inform decisions about future care preferences and wishes for people living in care homes.

This document has been produced to help care home staff to open up discussions about future care with frail older people living in care homes. This is important in case residents find themselves not being able to voice their preferences and wishes at a later date.

The document aims to enable discussions about such future care to take place between a resident, their family/other people important to them, and the caring team (GPs, nurses/ district nurses and care home staff). The document has some suggested questions that are useful to ask.

Wherever possible it is important to involve the resident, and the people who are important to them, in these discussions - even when a resident has dementia.

This is not a legal document. However, if in the future a decision regarding care needs to be made, the information in this document is available to decision makers.

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Name of resident: Mr John Bates

Date of birth: 10/01/1925

GPs name: Dr Raj Patel

Family member who is point of contact:

Name: Mrs Marie Bates

Address: 67 Furness Road, Lancaster, United Kingdom.

Postcode: LA1 4YG

Telephone Number: 01524 593 701

Has a power of attorney(s) been appointed? Yes X No ☐

If 'yes', please provide details:

Name: Moore and Grace Solicitors

Address: 15 Flyde Avenue, Lancaster, United Kingdom.

Postcode: LA1 1QR

Telephone Number: 01524 664 552

Has an advance statement or other document outlining personal wishes already been written?  
Yes X No ☐

Has an advance decision to refuse treatment (ADRT) been written? Yes ☐ No X

Discussions in this document are based around the care the frail older person themselves would want to happen towards the end of life. It is about preparing for the worst, while hoping for the best. Such knowledge is collectively gathered and recorded in this document.

**Do you (or, in the case of incapacity, your family member) have any particular wishes that you (or your family member) would want to achieve in the near future? If so, is there anything we can do to help with this?**

John said that he would like to talk to his friend in Australia, which he had done once a week for the past ten years. They had served in the Navy together, and he was worried that they would lose contact now that he was in a care home. John said that he supported Newcastle United, and would like to watch the football on the living room television when his team were playing. Although John had problems moving around at times, he would like to remain mobile when he could and not use a wheelchair.

**In the event of a gradual decline in health, is there anything that worries you (or, your family member), or that you (or, your family member) dreads happening?**

John talked about his worries about being in pain in the last hours of his life, and fears that he would not be able to breathe or have shortness of breath. Dr Patel provided reassurance that the care home staff could provide pain medication and ensure he could breathe.

**Are there any special wishes that you (or, your family member) would like us to know about when you (or, your family member) approach the end of life?**

Marie, John's daughter, said she had provided a statement of advance wishes already but was not sure if they applied in the care home, and was clear that she did not want her father admitted to hospital under any circumstances. Jenny Smith, the care home manager, confirmed that the statement of advance wishes was on file and that out of hours services would be informed of these wishes. Marie also said she would like to know immediately if there was a decline in her father's condition, so that she could organise her granddaughter coming down from Leeds.

**Do you (or, your family member) have a particular faith or belief system that is important to you (or them)? Would you like a priest/spiritual adviser to come and visit?**

John stated that he was not a religious man, and was not bothered about attending a church or having contact with a priest.



**At the very end of life, where would you (or your family member) like to be cared for?**

John also stated that he would prefer not be in hospital or transferred out of the care home, but would like to die in the home with his daughter and granddaughter with him.

**Is there any specific ritual/religious practice that you wish to happen following the death that you (or, your family member) would like to make known? For instance, funeral details, burial/cremation**

John said that he had talked about this in the past, but his daughter Marie said that he had not told her what he would like to happen. John said he would like to be cremated, and for his ashes to be scattered in Australia where he had served in the war. John did not want a big funeral, but a small ceremony would be fine.

**Summary of any further discussion**

The meeting went well, and gave an opportunity for Dr Patel and the care home staff to reassure John that they were prepared for pain management and alleviating shortness of breath. After the meeting, Marie thanked the care staff for the discussion, and said that without it she would not have known about her father's preferences following death.

**Care professional leading the discussion:**

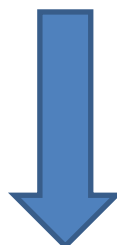
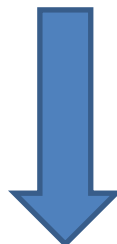
Name: Mrs Jenny Smith  
Role: Care home manager  
Date: 02/02/2018

**Please list those present at discussion:**

Name: Dr Raj Patel  
Relationship to resident: Doctor

Name: Miss Sally Jones  
Relationship to resident: Care assistant

Name: Mrs Marie Bates  
Relationship to resident: Daughter



#### Looking and Thinking Ahead

A document to inform decisions about future care preferences and wishes for people living in care homes.

This document has been produced to help care home staff to open up discussions about future care with frail older people living in care homes. This is important in case residents find themselves not being able to voice their preferences and wishes at a later date.

The document aims to enable discussions about such future care to take place between a resident, their family/other people important to them, and the caring team (GPs, nurses/ district nurses and care home staff). The document has some suggested questions that are useful to ask.

Wherever possible it is important to involve the resident, with the people who are important to them, in these discussions - even when a resident has dementia.

This is not a legal document. However, if in the future a decision regarding care needs to be made, the information in this document is available to decision makers.

\_\_\_\_\_  
Name of resident:

Date of birth:

GP's name:

Family member who is point of contact:

Name:

Address:

Postcode: Telephone Number:

Has a power of attorney(s) been appointed? Yes ☐ No ☐

If 'yes', please provide details:

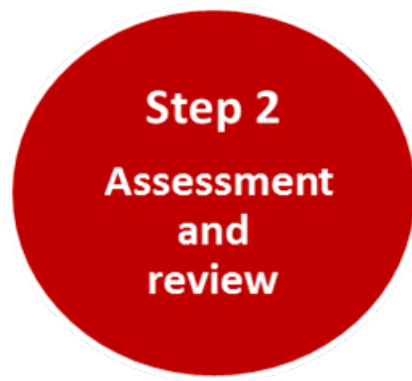
Name:

Address:

Postcode: Telephone Number:

Has an advance statement or other document outlining personal wishes already been written? Yes ☐ No ☐

Has an advance decision to refuse treatment (ADRT) been written? Yes ☐ No ☐



## Step 2: Using the 'Mapping Changes in a Resident's Condition' tool

Reviewing patterns of physical change towards the end of life is important in order to provide high quality palliative care that reflects the resident's preferences and choices.

### Objectives for staff to undertake Step 2

- Ensure every resident has a 'Mapping Changes in Resident's Condition' tool in their care plan.
- All staff to understand and know how to complete the 'Mapping Changes in Resident's Condition' chart.

### Assessment

When staff provide regular and ongoing care for a resident, they are able to recognise when a resident is deteriorating towards the end of their life. They can do this by recognising the clinical signs such as an increase in infections, frailty, observing a resident 'withdrawing' more into themselves, a lack of interest in eating, and increasing tiredness particularly when a resident seems to spend more time asleep than awake. Good assessment skills are important to identify a change in needs towards the end of a person's life whether these are physical, psychological, emotional or spiritual. They help staff **anticipate palliative care needs**.

### Reviewing patterns of change

When staff recognise a change in a resident's condition, they might not always know the exact reason for the deterioration, but they will often intuitively 'know' when a resident is ill and deteriorating. It is important to listen to how the resident is feeling, to hear what the family are saying as well as using your observation skills and intuition.

The 'Mapping Changes in Resident's Condition' tool plots deterioration and improvement in a resident's physical condition. The tool helps to empower staff to be able to visually recognise a resident's changing condition over months or weeks. By completing the 'Mapping Changes'

tool every month (and every week when a resident is in the last phase of his/her life) it will help support you to identify changes that can be seen in a resident's condition and viewed over a period of time.

## **ACTION**

- Implement the 'Mapping Changes' tool for each resident in order to recognise their current condition and ongoing changes.

## **TOOL**

- 'Mapping Changes in Resident's Condition' tool.

## Background for the facilitator

Assessment, care planning and review are part of everyday care for older people in care homes. Assessing and reviewing any palliative care needs helps to maintain a good quality of life for residents especially those who may be in the last year of life. It is important to start introducing the 'Mapping Changes in Resident's Condition' tool, which can start at any time.

### Helpful reminders for you

- Introduce the tool for every resident.
- It will help to plot changes in the resident's condition over time and visually show you whether a resident's condition is improving, deteriorating or just the same. It can start at any time, if no changes have occurred over the previous month this is indicated by a straight line.
- It should be completed every month by carers/nurses who care for the resident on a regular basis.

A useful time to complete the 'Mapping Changes in Resident's Condition' tool is before or at the monthly palliative care multidisciplinary review meeting (see Step 3).

### Barriers and solutions

Possible barriers to assessment and review during the last year of life	Solutions
Staff work in a care home to help older people wash and dress, and help them to live – to think that someone is in their last year of life is scary	For some staff, dealing with death and dying can be hard – however, most people living in care homes have advanced, progressive incurable diseases and many will die within a year of admission to a care home.
It is too difficult to predict when a frail older person will die	It is very difficult to know when an older person will die – however, there are physical signs when a frail older person is deteriorating.
Concerns about more documentation	The Mapping Changes in Resident's Condition tool has been tested in care homes in the seven PACE countries. Staff have found it helpful to 'plot' the 'changes' even though it can seem to be subjective, this is not a problem.

## Training session: Using the 'Mapping Changes in a Resident's Condition' tool

### Learning objectives:

- To understand the different trajectories and changes associated with frail older people in care homes in the last year of life.
- To learn how to complete the 'Mapping Changes in Condition' tool for each resident in the care home.

### Preparation

- Make sure that the flip chart is available.
- Bring enough 'Mapping Changes in Condition' tools so that every staff member present has one to practise on.

### Training and exercises

Read the following case study to highlight that the change in a resident's condition can be somewhat unpredictable – map the deterioration on the flip chart.

#### Case Study 1 – Marisa

Marisa had been living in her own home but over the past few months, her mobility had declined and she had been struggling to care for herself. She moved into a nearby care home in January.

It took her a couple of months to settle into the care home and she was really starting to enjoy the company of other residents and staff. However, in April, she fell on her way to the toilet, fractured her hip and went to hospital.

Following surgery to repair the fracture, she developed a chest infection, which delayed her recovery and meant that she was in hospital for three weeks. In May, she came back to the care home but she was not as well as when she had initially arrived at the care home.

After a couple of weeks back at the care home, Marisa started to improve. She was eating better and starting to mobilise by herself again. At the end of June, she had a wonderful visit from her sister who lived in Portugal. Shortly after her sister's visit, she developed a very bad chest infection and despite all efforts to treat the infection, Marisa's condition slowly deteriorated over the next few weeks and she died at the end of August.

## Discussion

- What are the advantages of being able to visually see representative changes in a resident's condition?
- What makes predicting death difficult?

Divide the group into pairs and give them one or other of the following two case studies and a blank 'Changes in Resident's Condition' tool. Ask them to plot the changes that occur in the case study on the tool.

### Case Study 2 – George

George moved into Greenside care home after the death of his wife. He was a reasonably healthy man and able to walk short distances independently. He was a kind and sociable man and he was helpful when new residents arrived and he quickly helped make them feel at home.

One day George complained of severe chest pain and was taken to hospital where they diagnosed that he had had a heart attack. He was in hospital for a week and then discharged back to the care home. He was happy to be back in his familiar surroundings but the staff noticed that he appeared to be physically a lot weaker.

He gradually started to improve but never quite returned to the same level of health that he was before his heart attack. One night, a member of the night staff found that George had died in his bed.

### Case Study 3 – Lars

Lars is an 85 year old man, who moved into a nearby care home six months ago. He had been struggling to care for himself at home after having a stroke, which had left him with a right sided weakness.

A couple of months later he had another stroke. His doctor assessed him, and felt that his condition had significantly deteriorated and he was dying.

His condition deteriorated within a week and he died during the early hours of the morning.

## Monthly 'Mapping Changes in Resident's Condition' chart

(Adapted from Macmillan 2004 – Foundations in Palliative Care)

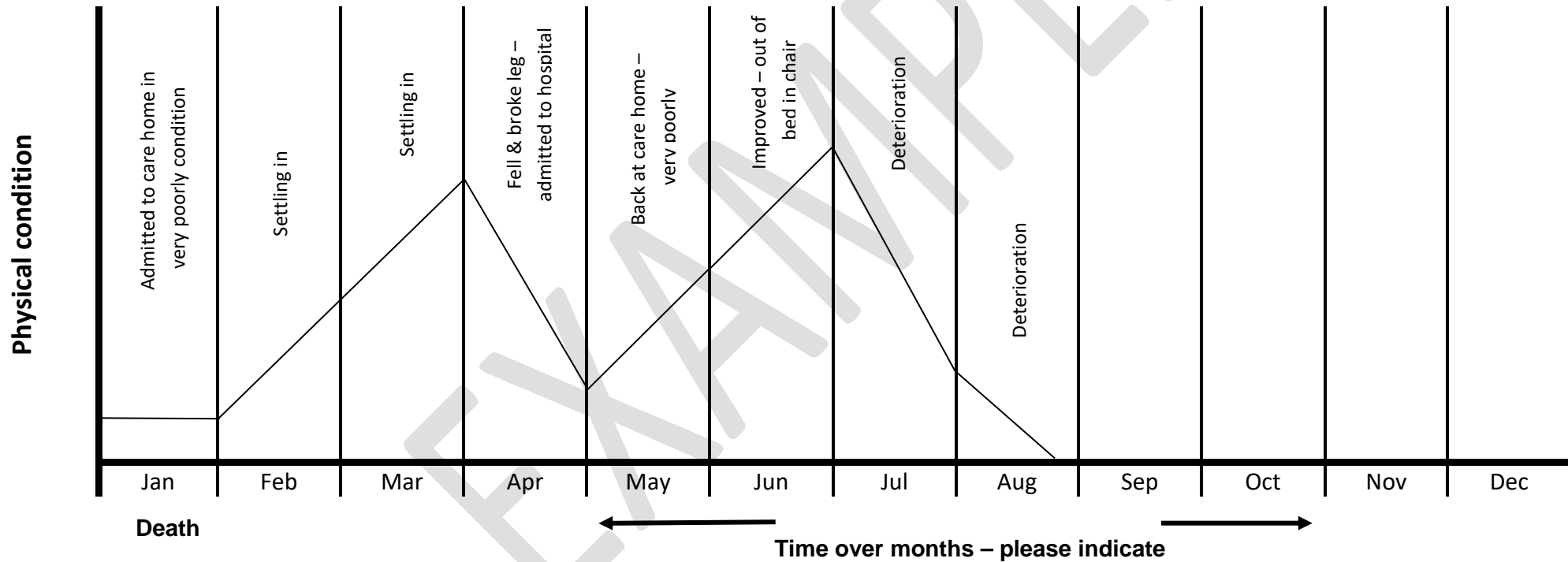
Resident's name: Marisa

Main Diagnosis: Hip fracture

Date tool commenced: January 2018

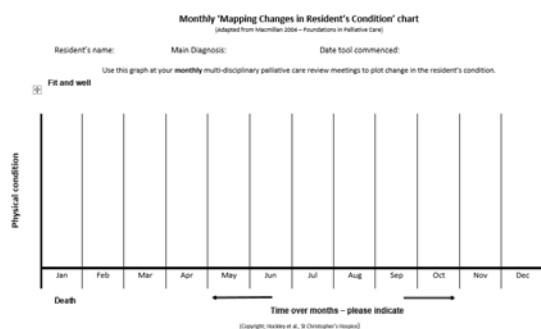
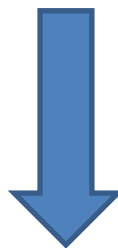
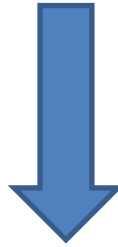
Use this graph at your **monthly** multi-disciplinary palliative care review meetings to plot change in the resident's condition.

**Fit and well**



(Copyright; Hockley et al., St Christopher's Hospice)







### **Step 3: Guidance on facilitating the ‘Monthly Palliative Care Review Meeting’**

Palliative care is a team approach and should be effectively coordinated. Good coordination of care can be improved by holding a regular monthly multi-disciplinary review meeting. Good coordination of care helps to foster a team approach that ensures that a resident’s needs and preferences are managed and respected effectively.

#### **Objectives for staff to undertake Step 3**

- Create a Palliative Care Register for the care home residents.
- Organise and notify care home staff and external teams and professionals about the monthly multi-disciplinary palliative care review meetings well in advance.
- Set monthly review meeting dates for the whole year.

Effective teams work well because everyone is working together with a shared goal. Good coordination of a resident’s care helps to ensure that care goals are carried out.

There are likely to be a number of health and social care professionals involved in a resident’s care, including: doctors, nurses, palliative care teams, dieticians and other disciplines. Some may work in the care home while some may just visit the care home. All these team members bring their own knowledge, skills and expertise. Working together as a team ensures the person gets the best palliative care possible.

Meeting as a multi-professional team **every month** not only helps to build teamwork and trust across the different professions but also helps to develop good coordination of palliative care. Those services providing ‘out of hours’ care need to be informed of the palliative care status of residents, so appropriate care is prioritised. Working with services providing support during the day, at night, and at weekends, is pivotal to providing seamless good quality palliative care.

Particular attention should be given to those residents thought to be in the last year of life and whether, if they were to die suddenly, they would want to be resuscitated or not. This is a clinical decision and, for frail older people living in care homes, it can be helpful if a decision is made in

advance of such a situation happening.

### **Coordination of care**

A simple **palliative care register** alongside a monthly multi-disciplinary palliative care review meeting can help coordinate good care in the last year of a resident's life. The register will prompt you to consider the different aspects of palliative care that might need further team discussion and follow up. The presence of the wider multi-disciplinary team at these meetings helps to ensure care is fully coordinated. A summary of the meeting is completed and sent to professionals not present.

### **ACTION**

- A monthly multi-disciplinary team meeting focusing on the palliative care needs of **all** residents is held every month. A 'summary sheet' is sent to those professionals that are unable to attend.

### **TOOL**

- Palliative Care Register

## Background for the facilitator

Nurses and care workers are able to identify the various signs that might indicate that a resident may be entering the last stage of their life.

We have provided a template for a Palliative Care Register. The names of **all residents** living in the care home can be recorded on it. The care home administrator can help with preparing the 'Palliative Care Register'. It will need to be updated regularly, perhaps electronically, and someone will need to take responsibility to make sure that it is up-to-date prior to the monthly meeting.

The ***Palliative Care Register*** contains information such as

- name, age, date of admission to care home, diagnoses,
- likely prognosis in terms of a broad judgement of years, months, weeks or days to live –this is often noted in the form of = **Y**ears; **M**=months; **W**=weeks; **D**=days,
- specific symptom issues and complex family interactions,
- which residents have had an advance care planning discussion and the date it was held,
- which residents have specialist palliative care referral if appropriate.

This register is used at the monthly review meetings where all residents are discussed and where the '**Mapping Changes in Resident's Condition**' tool can be quickly completed; many residents will not need a long discussion. For example, in a care home of 40 beds, this meeting should be completed within about 2 hours. A larger care home may need two review meetings a month in order to cover all residents.

An important aspect of this meeting is to consider whether a resident has deteriorated during the month, whether the resident might have years, months, weeks or days to live. To do this staff caring for the resident need to look back over the previous month/s at the resident's condition (not their diagnoses, nor their age) to see whether their condition has either improved, remains the same, or if there are signs of deterioration. Alongside this, you can use the surprise question "**would I be surprised if Mr Smith died in the next twelve months?**". Using both these things, alongside a member of staff being present who knows the resident well, can give a reasonably realistic understanding of a likely prognosis.

## Barriers and solutions

Potential barriers to coordination of care	Solutions
People feel there is not enough time to sit down once a month to discuss <b>all</b> the residents	By 'spending time' people find they 'save time' because difficult situations are anticipated and care is planned in advance.
People think they only need to discuss the 'ill' residents	By discussing <b>all</b> residents (briefly for those who do not appear to have a problem), if a resident suddenly deteriorates then there is a plan available for staff to know whether or not they wish to be sent to hospital.
The monthly palliative care review meeting is difficult to organise in a large care home	In large care homes, they can hold a monthly palliative care review meeting in each unit i.e. unit 1 on the first Wednesday of each month, unit 2 on the second Wednesday etc. The doctor may argue he/she cannot attend each unit each week. You could suggest they go to the most important unit for that month. If the care home already holds a regular multi-disciplinary meeting, then the Palliative Care register could be completed at that meeting.
Doctors feel they cannot spare the time to attend a monthly palliative care review meeting.	The meetings help to build good coordinated palliative care and improve relationships both <i>within</i> the care home, and with those external to the care home. If the doctor cannot attend a meeting, the summary sheet can be sent to them. The care home manager needs to discuss this meeting with the doctor to encourage attendance. Meetings can be arranged so the doctor only needs to attend for a short time when his or her patients are being discussed. Perhaps start by involving those doctors who are most involved in the care home.
Asking the 'surprise question' is hard. I do not want to say someone only has weeks to live in case it happens!	By looking back over the past months alongside asking the 'surprise' question, holds the key to understanding how a person really is. Most staff have a sense when someone might be dying (foreknowing) – unfortunately, they do not always tell the rest of the team (foretelling). By speaking openly together, this means that appropriate care is planned.
Death of a resident is seen as a failure of care	Assessing the care needs of residents and families specific to the last year of life can mean that the dying phase is anticipated. Being able to give good end-of-life care can be very rewarding.

## Training session: Guidance on facilitating the ‘Monthly Palliative Care Review Meeting’

### Learning objectives

- To organise the dates/time for the ‘Monthly Palliative Care Review Meeting’.
- Ensure the Palliative Care Register is completed and up-to-date.
- To facilitate and coordinate the ‘Monthly Palliative Care Review Meeting’.
- To inform any external health care professionals of any actions or follow up needed.
- To encourage participation and attendance by both care home and external health care staff.

### Preparation

The care home manager should inform the doctors and any other external health and social care professionals involved in a resident’s care about the introduction of the **‘Monthly Palliative Care Review Meeting’**. It is important that the dates for the monthly meetings are arranged well in advance with the dates and times communicated to all care home and external staff. Attendance of external health and social care professionals involved in a resident’s care needs encouraging, for example; doctor, palliative care specialist nurse, dietician, home care support team and other people involved.

Care staff should also be proactively encouraged to attend and participate in the monthly review meetings whenever possible. This helps to foster a wider team approach and ensure that those caring for residents on a daily basis are able to communicate any changes occurring in a resident’s condition.

It is important that the meeting is efficiently organised, so that those attending can make the most optimum use of their time and to encourage their ongoing future attendance.

Watch Resource Video Two: Role model of a ‘Monthly Palliative Care Review Meeting

### Suggestions for the efficient organisation of the meeting:

- Ensuring that residents are grouped together for discussion per medical practice and the **‘Palliative Care Register’** is up-to-date prior to the meeting.
- All necessary medical, nursing notes and medication charts are available.

- Identify someone to keep a check on time so that the momentum and focus is maintained throughout the meeting and to ensure that all residents are able to be discussed within the timeframe of the meeting.

If an external health care professional is unable to attend the monthly meetings, record any actions that require follow up on the **'Palliative Care Review Meeting Summary Sheet'** and forward using confidential channels.

## **Resources**

Resource Video Two: Role model of a 'Monthly Palliative Care Review Meeting

Resident name, age, DOA <sup>1</sup>	Diagnoses	Anticipated time to live [Y,M.W.D] <sup>2</sup>	Doctor	DNACPR decision date <sup>3</sup>	Future care plan discussion date <sup>4</sup>	Problems/Concerns Assessments Communication with resident /family	SPC/ hospice /other specialists <sup>5</sup>	Out of hours providers informed of EoL care date <sup>6</sup>	POC at EoL discussion date <sup>7</sup>	Last days of life documentation date <sup>8</sup>	Actual POD/ date <sup>9</sup>	Bereavement support necessary <sup>10</sup>
Mr John Bates, 90, 25/01/2018	Mild dementia, Skin cancer	1 year	Dr Raj Patel	15/01/18	02/02/18	Daughter very involved in care, lives locally.	N	05/02/18	02/02/18	05/02/18	Care home 11/11/18	Y
Mr Phillip Gorman 86, 09/12/2017	Stroke, COPD	3 weeks	Dr Sylvia Moore	N/A	N/A	Problems communicating since stroke, son involved but lives in London.	Y – speech therapist	N/A	N/A			
Mrs Laura Thompson, 89, 07/07/2017	Severe Dementia	3 months	Dr Ken Samuels	06/06/17	01/08/17	Completely deaf, no family, frequent UTIs	N	10/07/17	10/07/17			

1. Date of admission (DoA)
2. Anticipated time to live in years, months, weeks, days [Y,M,W,D]
3. Date when decision made not to attempt cardio-pulmonary resuscitation
4. Date when plans about future care first discussed
5. Specialist Palliative Care / hospice involvement +/- other specialists e.g. physio, social worker, dietitian etc

6. Date information re end-of-life (EoL) care sent to 'out of hours' providers
7. Place of care (PoC) at end of life (EoL) discussion + date
8. Date when documentation for assessment & management of last days of life commenced [or similar documentation]
9. Place of death (PoD)
10. Particular bereavement support for relative necessary? Y/N



## Summary sheet of monthly multi-disciplinary palliative care review meetings using Palliative Care Register

Care home/ floor Priory Care Home      Total number of residents to be discussed: 3

Name of GPs present: Dr Raj Patel      Date 30/02/2018

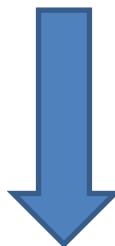
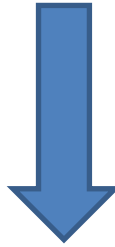
Names of staff present: 4

Name: Mrs Jenny Smith	Role: Care home manager
Name: Miss Sally Jones	Role: Care assistant
Name: Ms Katya Telpova	Role: Nurse
Name: Mr Kyle Simmons	Role: Care assistant

Number of residents reviewed	3
Number of residents still to have 'Looking and Thinking Ahead' documentation completed	1
Number of residents discussed with in-depth problems	1

### ACTION POINTS for specific residents with in-depth problems:

Resident name	Action to be taken by whom and by when	Outcome
Mr John Bates	Pain assessment to be carried out by Kyle Simmons in next week.	
Mrs Laura Thompson	Pain assessment to be carried out by Sally Jones in next week.	
Mr Phillip Gorman	Looking and Thinking Ahead document to be discussed by Jenny Smith in next month, with support from Katya Telpova. Jenny Smith to organise meeting with Dr Patel and relatives.	



**Summary sheet of monthly multi-disciplinary palliative care review meetings using Palliative Care Register**

Care home/ floor: \_\_\_\_\_ Total number of residents to be discussed: \_\_\_\_\_

Name of GPs present: \_\_\_\_\_ Date: \_\_\_\_\_

Names of staff present:

Name: \_\_\_\_\_ Role: \_\_\_\_\_  
Name: \_\_\_\_\_ Role: \_\_\_\_\_  
Name: \_\_\_\_\_ Role: \_\_\_\_\_

Number of residents reviewed	
Number of residents still to have 'Looking and Thinking Ahead' documentation completed	
Number of residents discussed with in-depth problems	

**ACTION POINTS for specific residents with in-depth problems:**

Resident name	Action to be taken by whom and by when	Outcome



## **Step 4: Delivery of high quality palliative care: symptom control - Pain**

Good palliative care includes good symptom control and residents being treated with compassion, dignity and respect at all times. This care puts the resident and family at the centre. Staff need to make sure that the right people do the right thing at the right time to help optimise residents' quality of life.

### **Objectives for staff to undertake Step 4**

- Become familiar with tools to assess pain.
- Identify residents who would benefit from assessment of pain and undertake an assessment.
- Involve care staff in assessments especially when residents have advanced dementia.

A palliative care approach emphasises good assessment of symptoms as a priority. All symptoms (such as pain, depression, delirium, constipation, anxiety) are important, but for the PACE Steps to Success Programme, we focus on good pain assessment as a starting point.

### **Pain**

Some diseases and conditions can create varying degrees of pain. Systematic pain assessment on admission and the use of structured assessment documents can contribute to effective pain assessment and management. It is important to remember that a number of different factors cause pain. Pain can have a combination of physical, emotional, social and spiritual elements. This is called 'total pain'. Understanding pain is very important and sometimes needs a team approach.

Dementia adds a further complication to the assessment of symptoms. Many people with advanced dementia cannot tell someone when they are in pain. In these situations, pain assessments require a knowledge of how someone behaves and moves. In addition, in some cases, it may be challenging to understand how people with moderate stages of dementia express or communicate about pain. Regardless of the severity of dementia, residents should be involved to the greatest extent possible in the assessment of pain. Talking to somebody who knows the resident well (e.g. family members) may help to understand how a person with more advanced stages of dementia communicates about pain or may help to interpret or detect subtle signs of pain based on their long-standing relationship with the person.

## **ACTION**

- Undertake a pain assessment for all current residents and on admission for all new residents to the care home.

## **TOOL**

- Care home 'Pain Assessment and Management' tool, including an observational assessment scale (**PAINAD**) for people with advanced dementia.

## Background for the facilitator

Frail older people living and dying in a care home generally have a number of different diseases, which cause symptoms. Care home staff must be involved in reporting symptoms and have some experience in the assessment of them. Being able to show the doctor an initial assessment of a symptom is important to their further assessment and management.

Attention to good symptom control underpins good palliative care and generally means good quality of life for residents and indeed their families. However, some residents in care homes cannot tell you about how well their symptoms are being controlled. Dementia adds a further complication to the assessment of symptoms. Many people with advanced dementia cannot tell someone when they are in pain. In these situations, pain assessments require a knowledge of their behaviour and expressions.

The pain assessment tools that can be used as part of the PACE Steps to Success Programme include:

- Care Home Pain Assessment tool
- PAINAD (for people who are unable to tell you about their pain)

**All** residents in the care home need to be assessed for pain, and all new residents assessed on admission. Assessment is continued regularly if pain is not controlled, and then every six months.

## Barriers and solutions

Potential barriers to delivering good quality palliative care in care homes	Solutions
It is the doctor's job to assess symptoms	In other settings such as hospitals, doctors are often responsible for assessing symptoms. However, in some care homes a doctor may not visit every day. Staff in care homes therefore take on this responsibility in order to alert the doctor to problems with symptoms. It is a team effort.
Some staff can think that a resident is just the 'complaining sort'.	No resident will complain for the sake of it – there is generally a reason why they are unhappy. Unhappiness could be due to pain or discomfort, constipation, not sleeping well at night or feeling anxious about something.

## Training session: Guidance on understanding the assessment and management of pain

It might be helpful to speak to your local palliative care team to ask if they would be able to help you deliver this training session. Involving other nurses and care workers in pain assessments is important, as often they know the residents well.

### Learning objectives:

- To reflect on the experience of pain.
- To understand the principles of pain assessment and management, and how to use a pain tool to record details of pain for frail older people living with or without dementia.

### Preparation

- Make sure flip chart is available.
- Bring enough pain assessment tools so that every member of staff at the training has one to look at and familiarise themselves with.

### Training exercise

#### *Exercise: The experience of pain*

Divide the group into pairs. Each person takes it in turns to describe:

- the worst pain they have ever had
- how it made them feel
- how it was treated

Feedback and discussion to include:

- the cause of the pain
- the difference between 'acute pain' and 'chronic pain' (chronic pain is any pain that lasts for more than 6 months)
- effect of emotions on pain
- importance of pain being 'what the resident says it is' and to remember not to make one's own judgements about someone else's pain
- the importance of doing something about the resident's pain

## Learn about the different causes and types of pain

Three main types:

**Somatic pain** (stimulation of receptors on the body surface - sub-cutaneous tissue) – generally localised and described as a dull ache in deep tissue, but more sharp in surface tissue pain.

- Bone pain – often specific over a bony area
- Muscle pain – often responds best to heat and massage

**Visceral pain** (internal organs in the body such as liver or abdomen – where there is stretching of the capsule causing pain) – not localised and often described as a squeezing type of pain

**Neuropathic pain (nerve pain)** (compression or destruction of nerves – very painful) - pain often spreads from area of compression i.e. around the waist, down a leg. Pain maybe experienced as ‘hot’ or ‘tingling’.

Get the group to talk about the types of pain experienced by residents living in care homes such as arthritis, stroke pain, cancer pain, constipation and osteoporosis pain.

Teach group about:

- **Pain Thresholds**
  - What lowers a person’s threshold of pain? (Answer: previous pain experience; other symptoms; bad night’s sleep; anxiety; depression; fear; isolation)
  - What raises a person’s threshold of pain? (Answer: companionship; control of other symptoms such as nausea and constipation; analgesics; anxiolytics; anti-depressants; good night’s sleep etc.)
- **Number of different pains:** Some residents might have more than one pain. Ask group to give an example of such a resident within the care home
- **Acute pain:** heart attack, chest pain or broken hip
- **Chronic pain:** often people learn to put up with pain. Many older people think pain is part of getting old so they often do not complain. Pain is **chronic** when it lasts for more than 6 months.

**PAIN IS MORE THAN JUST A PHYSICAL SENSATION.** It is important to understand ‘total pain’ and its four elements: **physical, psycho-emotional, spiritual and social pain** [6].

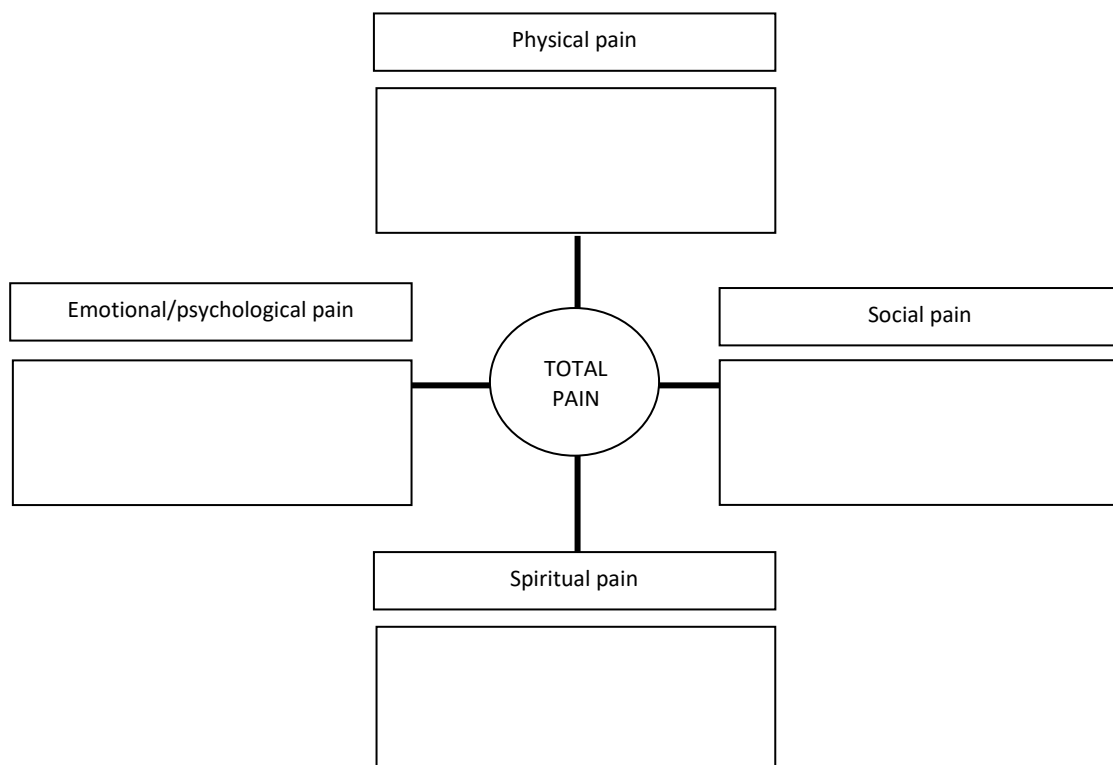
Give staff the following case study ‘**Sanna**’. Delegate one aspect of total pain to each group and invite them to identify that aspect of total pain from the case study.

#### Case Study 4 – Sanna

Sanna moved into the care home ten months ago. She used to be extremely outgoing and quite an extrovert person but now she requires help with washing and dressing. Although she manages to get to the dining room for lunch, her appetite is poor and she quickly goes back to her room because of the smell of her vaginal discharge. Sanna has lost weight, she feels tired and staff think that she appears to be depressed.

The doctor has prescribed antibiotics for a suspected urinary tract infection but there has been no improvement. Sanna has an appointment to see a gynaecologist. She is worried and this is keeping her awake at night. The doctor has not told Sanna of her suspicions about her condition but Sanna is starting to wonder if she has cancer.

After the group has discussed the case study, get them to add their understandings of Sanna's total pain to the flip chart using the '**Total Pain**' diagram as shown below:





Ask the group: **What factors result in a failure to control pain?**

Potential answers are:

- Belief that pain is inevitable when people are frail and older.
- Lack of proper assessment.
- Not believing a person when they say they are in pain.
- Lack of appreciation of how bad the pain is.
- Lack of training in understanding the assessment and management of pain.
- Analgesia not given regularly for chronic pain.
- Lack of knowledge about analgesics.
- Lack of understanding about the mental, emotional and spiritual aspects of pain.
- Nurses and carers are aloof to residents' needs.
- Staff too busy to provide care.
- Doctor does not work with the care home staff to treat pain.
- Doctor has lack of knowledge about pain assessment and management in older people.

**How often should pain be assessed?**

- On admission to the care home.
- Every week – if a resident is on analgesics.
- Every month – if pain is well controlled.
- Every day – if a resident is in pain.
- Reviewed every six months.
- Always check for anything else that could be causing discomfort for example constipation or urinary infection.

**Explanation of the 'Care Home Pain Assessment and Management' tool**

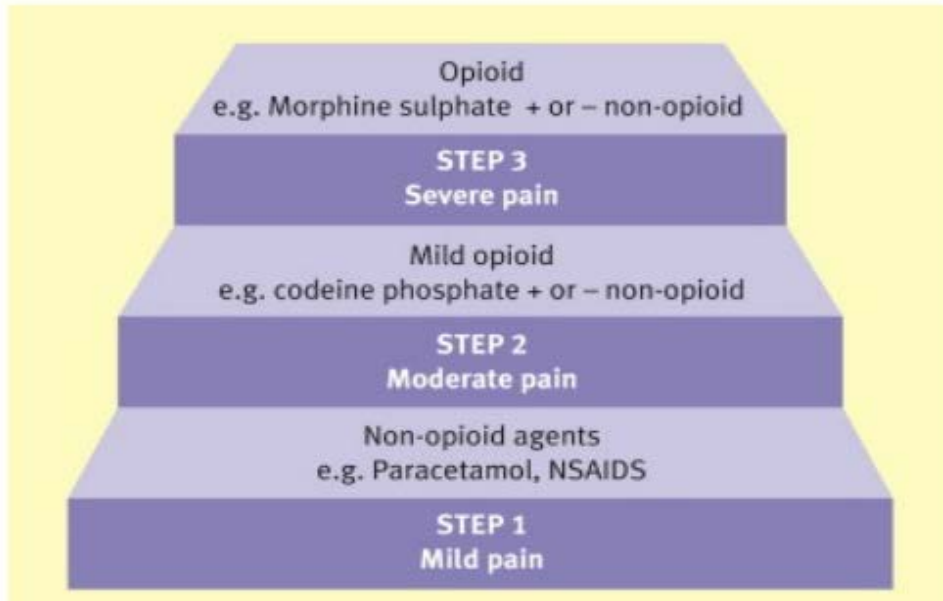
Get each person to look at the Care Home Pain Assessment and Management Chart:

- Page 1 - for people who have mental capacity and can answer the questions for themselves.
- Page 2 - to be used with people who cannot accurately talk about their pain and need assessment through observation of behaviours.
- Page 3 - record the management of the pain.

## Pain Management

Explain the WHO analgesic ladder [5].

# WHO Analgesic Ladder



**Step 1:** Non-opioids (paracetamol, non-steroidal anti-inflammatory medications)

**Step 2:** Weak opioids (most frail older people will need medicines on the second step of the ladder to control pain using codeine/paracetamol derivatives)

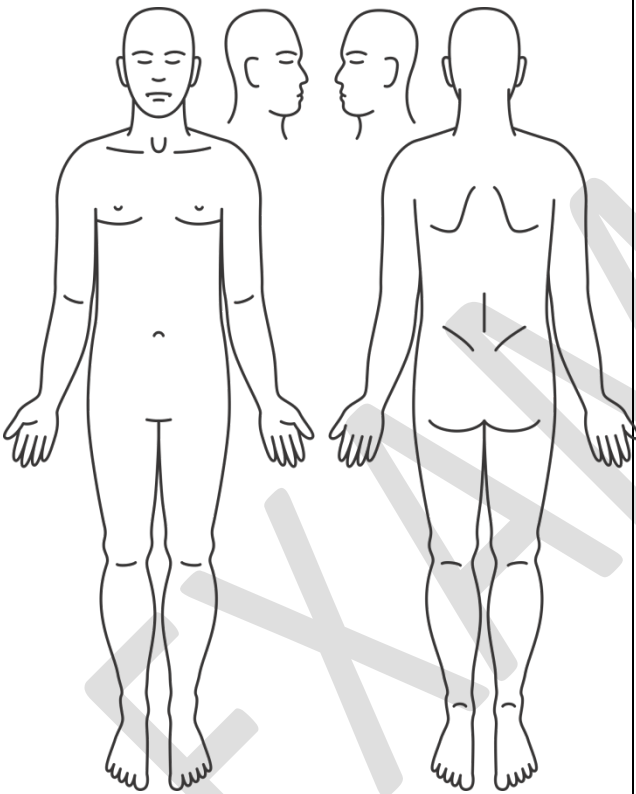
**Step 3:** Strong opioids (morphine and their different immediate release and slow release medicines that are given via oral and subcutaneous routes)

- Explain use of co-analgesics: steroids, anti-depressants, anti-convulsants.
- Explain use of trans-dermal patches to control mild to moderate pain in frail older people.
- Explain importance of giving laxatives to frail older people that are prescribed regular analgesics.

It is important to remember to **review the pain** and list the various medications used on the 3<sup>rd</sup> and 4<sup>th</sup> pages of the pain chart.

It might be helpful to get staff to talk about a case study of one of the residents that they believe to be in pain, to cover all aspects of pain.

## Care Home Pain Assessment and Management Tool (with PAINAD scale)

To be completed on each resident: on admission if resident taking pain killers; if resident appears in pain; and always at six-monthly review	
Name of care home: Priory Care Home	
Name of resident: Mrs Laura Thompson	
Date of admission: 07/07/2017	Date of first assessment: 05/03/2018
Current medications being taken by the resident: None	
	<p><b>Pain intensity scale</b></p> <p>If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?</p> <p><b>10</b> <input type="checkbox"/> The worst pain you have ever had</p> <p><b>9</b> <input type="checkbox"/></p> <p><b>8</b> <input type="checkbox"/> Very severe pain</p> <p><b>7</b> <input type="checkbox"/></p> <p><b>6</b> <input type="checkbox"/> Severe pain</p> <p><b>5</b> <input type="checkbox"/></p> <p><b>4</b> <input type="checkbox"/> Moderate pain</p> <p><b>3</b> <input type="checkbox"/></p> <p><b>2</b> <input type="checkbox"/> Mild pain</p> <p><b>1</b> <input type="checkbox"/></p> <p><b>0</b> <input type="checkbox"/> No pain</p>
<b>1 Where is or are your worst pain(s)?</b> Please mark the site of pain on the body tool above left.	
<b>2 How bad is the pain on the intensity scale?</b> Please tick the relevant box in the pain intensity tool above right.	
<b>3 How long has the pain been present?</b>	
<b>4 Does anything make the pain worse?</b>	
<b>5 Does anything make the pain better?</b>	

## Pain Assessment in Advanced Dementia (PAINAD) scale

Use this assessment tool when a person is unable to accurately describe their pain (Volicer & Hurley [7])				
Items	0	1	2	Score
<b>Breathing</b> (independent of vocalisation)	• Normal	• Occasional laboured breathing • Short period of hyperventilation	• Noisy laboured breathing • Long period of hyperventilation • Cheyne-Stokes respirations	0
<b>Negative vocalisation</b>	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	2
<b>Facial expression</b>	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	1
<b>Body language</b>	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out.	1
<b>Consolability</b>	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract or reassure	1
<b>TOTAL</b>				<b>5</b>
Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0='no pain' to 10='severe pain'). A total score of 2 or more indicates pain and requires action.				
<b>NB</b> Once you have 'scored' the pain make sure you document the necessary management on the next page				

### Definitions of some terms used in the PAINAD – please see Volicer & Hurley [7] for full explanation

**Breathing:** '*occasional laboured*' – episodic bursts of harsh/difficult respirations; '*short period of hyperventilation*' – intervals of rapid, deep breaths lasting a short period of time; '*noisy laboured*' – negative-sounding respirations on inspiration & expiration appearing strenuous which may be loud, gurgling or wheezing; '*long period of hyperventilation*' – excessive rate/depth of respirations lasting a long time; '*Cheyne-Stokes*' – waxing and waning of breathing from very deep to shallow respirations with periods of apnoea.

**Negative Vocalisation:** '*occasional moan/groan*' – mournful/murmuring sounds, wails or laments – groaning is involuntary often abruptly beginning & ending; '*low-level speech with a negative or disapproving quality*' – muttering, mumbling, whining, grumbling or swearing; '*repeated troubled calling out*' – repetitive words in an anxious, uneasy or distressed tone; '*loud moaning or groaning*' – mournful/murmuring sounds, wails or laments in a louder volume than usual often abruptly beginning or ending; '*crying*' – emotion accompanied by tears which can be sobbing or quiet weeping

**Facial Expression:** '*sad*' – unhappy/sorrowful/dejected look; '*frightened*' – a look of fear/alarm or heightened anxiety; '*frown*' – increased facial wrinkling in forehead or around mouth; '*facial grimacing*' – distorted/distressed look.

**Body Language:** lying still and afraid to move, or very restless

**Consolability:** able to be reassured

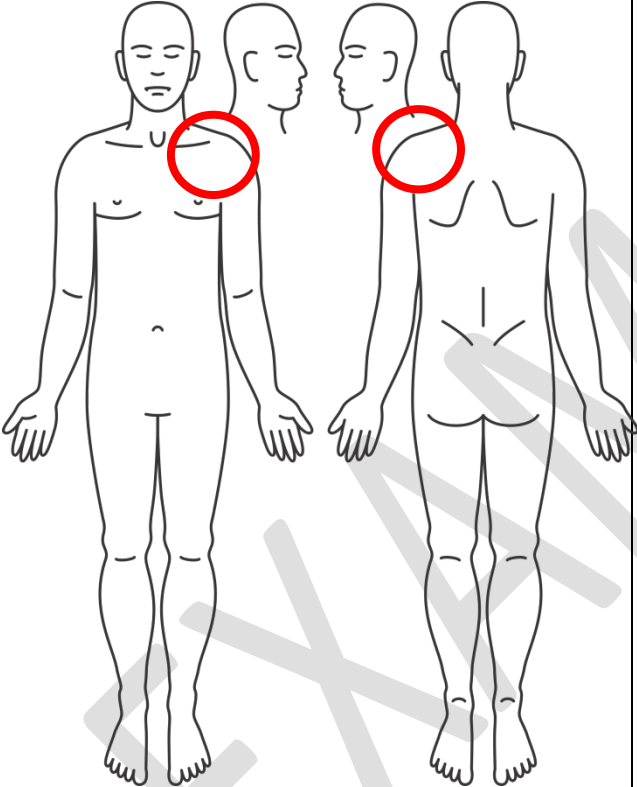
## Pain re-assessment and management

<b>Name of resident:</b> Mrs Laura Thompson
<b>Name of care home:</b> Priory Care Home
<b>Resident must be assessed:</b> <input checked="" type="checkbox"/> daily <input type="checkbox"/> weekly <input type="checkbox"/> monthly (please tick relevant box)
<b>Current medications being taken by the resident:</b> None

**PAIN INTENSITY QUESTION** If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?

Date	Time	Pain intensity 1-10	PAINAD score	Action taken	Date bowels last opened	Signature and review date/time	Outcome
05/03/18	1600	N/A	5	Paracetamol	05/03/18	Sally Jones 07/03/18 1600	Appears more comfortable
07/03/18	0900	N/A	2	Paracetamol	06/03/18	Sally Jones 07/03/18 1400	Appears more comfortable
08/03/18	1400	N/A	1	Paracetamol	06/03/18	Sally Jones 10/03/18 1800	

## Care Home Pain Assessment and Management Tool (with PAINAD scale)

To be completed on each resident: on admission if resident taking pain killers; if resident appears in pain; and always at six-monthly review	
Name of care home: Priory Care Home	
Name of resident: Mr John Bates	
Date of admission: 25/01/2018	Date of first assessment: 05/03/2018
Current medications being taken by the resident: Paracetamol as required	
	<p><b>Pain intensity scale</b></p> <p>If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?</p> <p>10 <input type="checkbox"/> The worst pain you have ever had</p> <p>9 <input type="checkbox"/></p> <p>8 <input type="checkbox"/> Very severe pain</p> <p>7 <input type="checkbox"/></p> <p>6 <input checked="" type="checkbox"/> Severe pain</p> <p>5 <input type="checkbox"/></p> <p>4 <input type="checkbox"/> Moderate pain</p> <p>3 <input type="checkbox"/></p> <p>2 <input type="checkbox"/> Mild pain</p> <p>1 <input type="checkbox"/></p> <p>0 <input type="checkbox"/> No pain</p>
1 Where is or are your worst pain(s)? Please mark the site of pain on the body tool above left.	
2 How bad is the pain on the intensity scale? Please tick the relevant box in the pain intensity tool above right.	
3 How long has the pain been present? On and off for the past year, worse in winter.	
4 Does anything make the pain worse? Not moving the arm for a long period, being cold.	
5 Does anything make the pain better? Heat pads, mild exercise.	

## Pain Assessment in Advanced Dementia (PAINAD) scale

Use this assessment tool when a person is unable to accurately describe their pain (Volicer & Hurley [7])				
Items	0	1	2	Score
<b>Breathing</b> (independent of vocalisation)	• Normal	• Occasional laboured breathing • Short period of hyperventilation	• Noisy laboured breathing • Long period of hyperventilation • Cheyne-Stokes respirations	N/A
<b>Negative vocalisation</b>	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	N/A
<b>Facial expression</b>	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	N/A
<b>Body language</b>	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out.	N/A
<b>Consolability</b>	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract or reassure	N/A
<b>TOTAL</b>				N/A
Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0='no pain' to 10='severe pain'). A total score of 2 or more indicates pain and requires action.				
<b>NB</b> Once you have 'scored' the pain make sure you document the necessary management on the next page				

### Definitions of some terms used in the PAINAD – please see Volicer & Hurley [7] for full explanation

**Breathing:** '*occasional laboured*' – episodic bursts of harsh/difficult respirations; '*short period of hyperventilation*' – intervals of rapid, deep breaths lasting a short period of time; '*noisy laboured*' – negative-sounding respirations on inspiration & expiration appearing strenuous which may be loud, gurgling or wheezing; '*long period of hyperventilation*' – excessive rate/depth of respirations lasting a long time; '*Cheyne-Stokes*' – waxing and waning of breathing from very deep to shallow respirations with periods of apnoea.

**Negative Vocalisation:** '*occasional moan/groan*' – mournful/murmuring sounds, wails or laments – groaning is involuntary often abruptly beginning & ending; '*low-level speech with a negative or disapproving quality*' – muttering, mumbling, whining, grumbling or swearing; '*repeated troubled calling out*' – repetitive words in an anxious, uneasy or distressed tone; '*loud moaning or groaning*' – mournful/murmuring sounds, wails or laments in a louder volume than usual often abruptly beginning or ending; '*crying*' – emotion accompanied by tears which can be sobbing or quiet weeping

**Facial Expression:** '*sad*' – unhappy/sorrowful/dejected look; '*frightened*' – a look of fear/alarm or heightened anxiety; '*frown*' – increased facial wrinkling in forehead or around mouth; '*facial grimacing*' – distorted/distressed look.

**Body Language:** lying still and afraid to move, or very restless

**Consolability:** able to be reassured

## Pain re-assessment and management

<b>Name of resident:</b> Mr John Bates
<b>Name of care home:</b> Priory Care Home
<b>Resident must be assessed:</b> <input checked="" type="checkbox"/> daily <input type="checkbox"/> weekly <input type="checkbox"/> monthly (please tick relevant box)
<b>Current medications being taken by the resident:</b> Paracetamol  

**PAIN INTENSITY QUESTION** If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?

Date	Time	Pain intensity 1-10	PAINAD score	Action taken	Date bowels last opened	Signature and review date/time	Outcome
05/03/18	0900	6	N/A	Given paracetamol	05/03/18	Kyle Simmons 07/03/18 1600	Still showing signs of pain
07/03/18	1600	4	N/A	Given Ibuprofen and a heat pad	06/03/18	Kyle Simmons 07/03/18 1400	Still showing signs of pain
08/03/18	1500	2	N/A	Given Ibuprofen and a heat pad	06/03/18	Kyle Simmons 10/03/18 1800	Laxatives provided, looks more comfortable

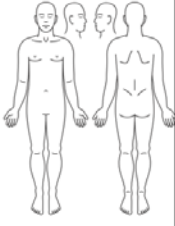




Care Home Pain Assessment/Management Tool (with PAINAD scales)

To be completed on each resident: on admission if resident taking pain killers; if resident appears in pain; and always at six-monthly review

Name of care home	
Name of resident	
Date of admission	Date of first assessment
Current medications being taken by the resident	



**Pain intensity scale**  
If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?

10 ☐ The worst pain you have ever had

9 ☐

8 ☐ Very severe pain

7 ☐

6 ☐ Severe pain

5 ☐

4 ☐ Moderate pain

3 ☐

2 ☐ Mild pain

1 ☐

0 ☐ No pain

1 Where is or are your worst pain(s)? Please mark the site of pain on the body tool above left ▲

2 How bad is the pain on the intensity scale? Please tick the relevant box in the pain intensity tool above right. ▲

3 How long has the pain been present?

4 Does anything make the pain worse?

5 Does anything make the pain better?



## **Step 5: Care in the last days of life and the process of dying**

For some residents, the dying phase might happen suddenly, but for the majority it is a slow, gradual process. It is important that staff recognise when a resident may be dying.

### **Objectives for staff to undertake Step 5**

- Death and dying are openly acknowledged by all staff in the care home.
- **All nursing and care assistant staff** need to attend a training session on the process of dying using the best practice scenario.
- Understand the three phases in dying: recognising dying, peripheral shutdown and central shutdown.
- Help care home staff feel more supported when a resident is dying.
- Actively encourage staff to sit with imminently dying residents to help support the family.
- Make sure that anticipatory medication to control symptoms in the last days of life is always prescribed as appropriate for each resident who is dying.

Recognising the dying phase is important if a resident is going to receive high quality palliative care at the end of life. Effective monitoring and assessment of the resident's condition over time using the palliative care register enables both the multi-disciplinary team, and families, to recognise when a person is deteriorating.

Making time for discussions with the resident (as appropriate), relatives, friends and other members of staff is important to ensure that everyone knows what to expect during the final days. Recognising and understanding the process of dying including how the body changes and systems close down over the last few days of life, can help families feel less frightened. This will help families realise that staff in the care home know what to anticipate. Often families find it difficult not seeing their relative eating and drinking. Staff need to help families understand that a dying person loses the desire for food and drink.

Using an assessment 'checklist' for the management of the last days of life alongside normal care plans can ensure that residents and their family get the best possible care at what can be a frightening time. All care staff can be trained how to use the checklist. The checklist prompts and

guides the care, and makes sure that appropriate medication is available in anticipation of any symptoms during the dying process. Having such a document can ensure that possible future changes in health status have been anticipated and appropriate medication made available, in case it is needed.

The checklist will help ensure that the doctor and pharmacist, who may work outside the care home, are aware of what might be required. It also prompts notifying services working 'out of normal hours' about the situation, ensuring that everyone involved, including the family, are aware of the changing condition.

## **ACTION**

- Use of an **Assessment 'checklist' for the Management of the Last Days of Life**, alongside the normal care plan, on residents who only have a few days to live.

## **TOOL**

- **Assessment 'checklist' for the Management of the Last Days of Life** or other such documentation already available.

## Background for the facilitator

This Step is about achieving a peaceful, dignified death for frail older people dying in care homes.

Staff need support in the care of residents who are dying. It is important to encourage an openness about dying. Use the word 'dying' at staff handovers and at meetings, instead of words such as 'deteriorating' or 'more poorly'. If *you* cannot use the word 'dying' it will be difficult to develop palliative care to a satisfactory standard in the care home. Speaking openly about dying is a measure of acceptance of the situation and an important part of setting goals of care and roles for staff and family members.

Read the '**best practice**' scenario to ensure that you are familiar and aware of all the important signs to look out for during the dying process.

### It is important that:

- **All nursing and care assistant staff** are trained (day staff and night staff) in the care of dying residents using the 'best practice' scenario.
- This training should be available when new staff arrive at the care home.
- **All nursing and care assistant staff need to understand the process of dying**, in order to support families better in what to expect.

Most frail older people will be aware they are dying. They do not necessarily need to be told this but often just listened to. 'Being present' with the resident and the family during the final stage of dying can be very comforting for families as many have not experienced a death before. Nurses and care workers play a vital role in providing the right environment to achieve a good death in a care home.

## Barriers and solutions

Potential barriers to good care in the last days of life	Solutions
Staff are scared to sit with a resident who is dying as they have never seen a death before	Explain the situation to them and 'where the resident is at' in the process of dying. If possible go with them, explain what is happening, and see if they will sit there for a short while.
Sitting with dying residents and their families is difficult as staff do not always know what to say	Being present when a resident is imminently dying often does not need words. Just being there is important.
Staff cannot predict when someone will die and may not recognise it until very late	Learning about the 3-stage process of dying can help care staff better judge when a person is dying and when the death will occur.
Staff are concerned about pain management	Appropriate pain management is important, and the type of analgesia required will vary for each individual. There are a range of different ways to deliver pain medication if a person is too ill to take medication orally.
Staff already have implicit assumptions about what dying is like	Help to challenge assumptions about what dying involves and assess individual needs.

## **Training session: Care in the last days of life and the process of dying**

### **Learning objectives**

- To fully understand the process of dying.
- To be able to recognise dying more effectively.
- To feel more comfortable sitting with a dying person and comforting family members.

### **Preparation**

- All nursing and care assistant staff members must be informed about the dying process.
- Make sure each staff member attending has a copy of the scenario and the checklist for the last days of life.

### **Training and exercises**

#### **Assessment and management for the last days of life**

- Give all nursing and care assistant staff a copy of the 'Assessment checklist for the Management of the Last Days of Life and Process of Dying' [7].
- Ask them if the checklist supports or challenges any assumptions they have about dying.

#### **Instructions for use**

- This scenario is given to each staff member along with the checklist to be completed during the last days of life.
- Suggest staff can underline in pencil anything that 'jumps out at them' as they read the scenario or they find interesting in relation to the last days of life.
- Ask members of the group what they felt was significant about the scenario.

## Process of Dying

### **Recognising dying – resident may have weeks to live:**

*Spending more of the day asleep rather than awake*

*No longer interested in eating*

*Drinking insufficient amounts*

### **Peripheral Shutdown – resident may have days to live:**

*Semi-conscious*

*Pinched nose*

*Laboured breathing*

*Bluish and cold extremities or mottling on skin – person does not feel cold themselves and can appear restless which is often caused by them feeling too hot*

*'Death rattle' – inability to cough up tracheal secretions*

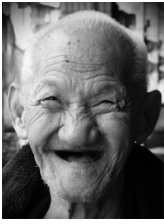
### **Central shutdown – imminent dying – resident may have hours to live**

*Comatosed*

*Thin and thready pulse*

*Breathing becomes 'shallow'*

## ‘Recognising Dying’



Xavier Peeters is a 97-year old man who has been living in a care home for the past 18 months. Three months ago Xavier fell and broke his hip. He was admitted to hospital where he had an operation to repair it.



When he went back to the care home, he struggled to move around and lacked any energy or motivation to get out of bed. The nurse, Lea went to talk to him to check that everything was ok. He told her that he had a lot of pain whenever he tried to move. Lea, used the **Pain Assessment tool** to record the severity of his pain prior to giving him medication to help him.



Over the past few weeks, his pain has been better. He has recently had a couple of chest infections that required oral antibiotics. Lea thinks that his physical health has deteriorated; he shows no desire to eat and needs encouragement to drink. She decides to review how he has been over the past few weeks using the **‘Mapping Changes in Condition’ chart** and it helps to confirm her thoughts.



Over the past two weeks, Xavier has hardly eaten anything and has been having difficulty taking his tablets. His son lives a few hours away but visits every fortnight, his son had noticed a change in his father’s condition as well and he asked if he could speak to the doctor after he had reviewed him.



During the **monthly palliative care review meeting** Lea shares her thoughts and observations with the team. She mentioned that Xavier’s son had been surprised to see the decline in his father. He asked to be kept informed of any changes. The GP agrees to review Xavier and arrange to speak to Xavier’s son.

### Group Discussion – recognising dying

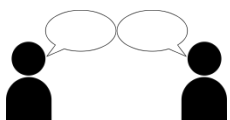
- What makes you think that Xavier might be in the last week/s of life?
- What makes you think he might be dying?



## 'Diagnosing dying'



The following morning the doctor arranges to visit Xavier, she talks to the nurse who tells her that overnight he has become increasingly restless. She examines Xavier, and whilst listening to his chest she notices that he is hot to touch. When she tries to speak to him she gets no real response other than him just staring at her.



After examining Xavier, the doctor says that he has another chest infection. She is not sure whether another course of antibiotics is appropriate. The doctor is aware that prior to Xavier's operation, resuscitation was discussed with Xavier and his son and he has completed a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) form. The doctor contacts Xavier's son to update him.



After discussion with Xavier's son and the wider care team, it is decided that the goal of care, is to keep Xavier as comfortable as possible. As a team, they now acknowledge that Xavier is actively dying, his son is aware and he plans to visit him tomorrow and asks to be kept informed of any changes. The nurse starts the '**care in the last days of life**' checklist and updates his plan of care.



Oral medications have been stopped due to his inability to swallow but a transdermal analgesic patch is used to control his pain. The doctor prescribes paracetamol suppositories for his high temperature, and sub-cutaneous morphine in case Xavier needs more pain relief. Sometimes when people are dying they can get a build-up of tracheal secretions (death rattle) so the doctor prescribes medication (Glycopyrronium) as required.



The staff help to make sure that Xavier is comfortable and pain free. They know that he likes to listen to the birds singing outside so they leave his window open. Lea lets Xavier know that his son is coming to visit him the following day as she knows that he has a close relationship with his son.

### Group Discussion – diagnosing dying

- What aspects from this scenario highlight the important role of the nurse in the care of dying residents and their families?
- When a frail older person is dying, what symptoms may need to be addressed?



The care staff keep a close check on him overnight providing regular pressure area and mouth care as well as assessing him for any other symptoms he might have. He remains peaceful and sometimes wakes up. His pulse is reasonably strong. Xavier is not a religious man but when Lea had previously talked to him prior to his fall, he told her how he gets inner strength through his love of nature and also from his son.



The staff have noticed that Xavier has some tracheal secretions, his feet are cold and his skin is a mottled purple colour. His breathing is also quite laboured. They give him medication for his tracheal secretions and change his position. They update his son of the changes; he is keen to be with his father as soon as possible.



Xavier is deteriorating; his pulse is now weak and thready. His son arrives and Lea sits with both of them for a while, prepares his son a drink and makes sure he is all right. She lets him know that the staff are nearby if he needs anything.



His breathing is shallow and his pulse weak and thready. Lea knows that he is imminently dying; she makes sure the other staff are aware too. She sits with Xavier and his son. Within half an hour Xavier's breathing has gradually stopped, he looks very peaceful. The nurse remains with Xavier and his son, and she confirms that he has died. Xavier's son stays with his father. Lea offers her condolences and makes sure that he knows staff are nearby.

### **Group Discussion – final process of dying: peripheral and central shutdown**

- What physical change occurs with peripheral shutdown? What is happening in the body at this point?
- What physical changes occur in central shutdown? What is happening in the body at this point?
- What are the important things we need to remember following the death of a resident?

## Assessment checklist for the Management of the Last Days of Life & Process of Dying

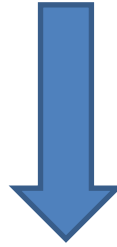
Care home/floor: Priory Care Home

Resident name: Mr John Bates

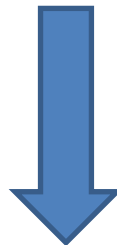
Checklist	Date
1. Team discussion/recognition that the resident may now be dying. The following things may be seen: <ul style="list-style-type: none"> <li>• Repeated infections</li> <li>• Weight loss</li> <li>• Lack of interest in life</li> <li>• Spending more time asleep during day than awake</li> <li>• Reduced food/fluid intake</li> <li>• Reversible treatments considered and deemed inappropriate</li> </ul>	01/11/2018
2. Senior and/or GP speak with family/next of kin <ul style="list-style-type: none"> <li>• Dignity and comfort as the goal of care with death in the care home</li> <li>• Decision regarding 'do not attempt cardio-pulmonary resuscitation' made</li> </ul>	06/11/2018 (DNACPR dated 15/02/2018)
3. Anticipatory medication for symptoms in last days of life prescribed and available in care home <ul style="list-style-type: none"> <li>• Appropriate anticipatory medication (sub-cutaneous or suppositories) for anxiety, respiratory secretions. and/or pain prescribed</li> <li>• All unnecessary medication discontinued</li> </ul>	06/11/2018
<b>On-going care [detail in care plan]</b>	
4. Hydration <ul style="list-style-type: none"> <li>• Resident encouraged to take fluids, ice cream, jelly by mouth as able (if aspirating consider crushed ice in gauze to suck)</li> <li>• Regular mouth care – involve family as appropriate</li> <li>• In rare circumstances sub-cutaneous fluids may be appropriate after discussion with GP/palliative care team</li> </ul>	06/11/2018
5. Regular 2 hourly care being carried out with regard to: <ul style="list-style-type: none"> <li>• restlessness</li> <li>• pain</li> <li>• noisy breathing</li> <li>• turning to prevent stiffness other</li> </ul>	10/11/2018
6. Spiritual needs attended to whether Christian, Muslim, Jewish and any other faiths ( <b>see resource folder for information</b> ) <ul style="list-style-type: none"> <li>• Christian – priest/chaplain called especially if in the past the resident went to church</li> <li>• Muslim – family generally very involved and often want funeral within 24 hours of death</li> <li>• Jewish – family generally inform Rabbi – special attention to last offices</li> </ul>	10/11/2018
7. Psycho-social spiritual support <ul style="list-style-type: none"> <li>• Resident – sensory input (music, scents, touch, being read to) also:               <ul style="list-style-type: none"> <li>• Not to be left alone in final process of dying (see overleaf).</li> <li>• Talk to resident i.e. when turning and re-positioning. Hearing is active until moment of death.</li> <li>• Many residents are aware that they are dying often using symbolic language. Detail in care plan. Do not be afraid to talk about dying if they make reference to it.</li> </ul> </li> <li>• Family – continual communication about process of dying prepare them for being present at time of death (<b>see 'Process of Dying' diagram</b>)</li> </ul>	10/11/2018
8. At death <ul style="list-style-type: none"> <li>• Comfort family/next of kin</li> <li>• Inform GP</li> <li>• Communicate death with all staff and other residents</li> <li>• Organise day/time for team 'reflective de-brief'</li> </ul>	11/11/2018

## Step 5

### Care in the last days of life



## Implement: 'Last Days of Life' checklist



Assessment checklist for the Management of the Last Days of Life & Process of Dying

Care home/floor:	Resident name:	
Checklist		Date
<b>1. Team discussion/recognition that the resident may now be dying. The following things may be seen:</b> <ul style="list-style-type: none"> <li>Repeated infections</li> <li>Weight loss</li> <li>Lack of interest in life</li> <li>Spending more time asleep during day than awake</li> <li>Reduced food/fluid intake</li> <li>Reasonable treatments considered and deemed inappropriate</li> </ul>		
<b>2. Senior and/or GP speak with family/next of kin</b> <ul style="list-style-type: none"> <li>Dignity and comfort as the goal of care with death in the care home</li> <li>Decision regarding 'do not attempt cardiopulmonary resuscitation' made</li> </ul>		
<b>3. Anticipatory medication for symptoms in last days of life prescribed and available in care home</b> <ul style="list-style-type: none"> <li>Appropriate anticipatory medication (subcutaneous or suppositories) for anxiety, respiratory secretions, and/or pain prescribed</li> <li>All unnecessary medication discontinued</li> </ul>		
<b>Ongoing care (detail in care plan)</b>		
<b>4. Hydration</b> <ul style="list-style-type: none"> <li>Resident encouraged to take fluids, ice cream, jelly by mouth as able (if aspirating consider crushed ice in guaze to suck)</li> <li>Regular mouth care - moisten family as appropriate</li> <li>In rare circumstances subcutaneous fluids may be appropriate after discussion with GP/practitioner care team</li> </ul>		
<b>5. Regular 2 hourly care being carried out with regard to:</b> <ul style="list-style-type: none"> <li>restlessness</li> <li>pain</li> <li>noisy breathing</li> <li>tempting to prevent distress other</li> </ul>		
<b>6. Spiritual needs attended to whether Christian, Muslim, Jewish and any other faiths (see resource folder for information)</b> <ul style="list-style-type: none"> <li>Christian - priest/chaplain called especially if in the past the resident went to church</li> <li>Muslim - family generally very involved and often want funeral within 24 hours of death</li> <li>Jewish - family generally inform Rabbi - special attention to last offices</li> </ul>		
<b>7. Psychosocial spiritual support</b> <ul style="list-style-type: none"> <li>Resident - usually about music, stories, touch, being read to, etc:</li> <li>Not to be left alone in final process of dying (see overhead)</li> <li>Talk to resident i.e. when lying and re-positioning, hearing is active until moment of death</li> <li>Many residents are aware that they are dying often using symbolic language. Detail in care plan. Do not be afraid to talk about dying if they make reference to it.</li> <li>Family - continued communication about process of dying prepare them for being present at time of death (see: <i>Process of Dying</i>, <i>Disposal</i>)</li> </ul>		
<b>8. At death</b> <ul style="list-style-type: none"> <li>Comfort family/next of kin</li> <li>Inform GP</li> <li>Communicate death with all staff and other residents</li> <li>Discourage day/time for team reflective debrief</li> </ul>		



## **Step 6: Care after death**

Good palliative care does not stop at the point of death. When a resident dies, all staff need to follow good practices for the care of the body as well as being responsive to family wishes. The support and care provided to relatives or close friends of the deceased at this time will help towards coping with their loss. It is also important for other residents and staff to feel supported, some will have become emotionally connected to the resident who has died.

### **Objectives for staff to undertake Step 6**

- Undertake Reflective Debriefing sessions.
- Support the practice of regular Reflective Debriefing sessions by staff.
- Ensure the Reflective Debriefing tool is freely available.
- Make sure that the Death Audit Tool is complete.

Most families and close friends of the deceased will need help and emotional support around what to do after the death. Giving written information will help guide grieving people at a time when they are less likely to remember what is being said. Making contact a few weeks after death can be supportive. Inviting bereaved relatives and close friends back for an annual memorial event can also be helpful.

It is also important to remember that the resident who has died may have formed close friendships with other residents in the care home especially if they have known each other for some years. Ensure that these residents have support after the death and given an opportunity to grieve.

It is normal for care staff to be affected by the death of the person that they have cared for, especially when they have known them for a long time. It can be a frightening time especially for any member of staff who has not experienced a death before. Reflection allows us to remember the person. Besides being supportive of staff who often experience a number of deaths, a 'reflective debriefing' session can also enable staff to learn from practice. These sessions will help staff think through what went well, what did not go so well, what can be learned and the associated feelings of staff. Feelings play an influential role in how we care for people and so it is important not to ignore them. Endings are important for everyone.

Care home staff must feel confident in knowing how to deal with a situation after a resident has died. Enabling a resident who had become a close friend with the deceased to see the body can sometimes be very helpful. This should also be considered if the resident has dementia. Dealing with grief and loss is also important for residents with dementia. Residents should be provided with appropriate support to help them understand that a close friend has died and how to cope with that loss. This may include telling them about the death and then escorting them to see the body, if that is possible and something they would like to do. Consider the wellbeing and the wishes of the resident with dementia when providing the support. Different approaches may be necessary for different people. Some residents with dementia may not be able to express their emotions, feel distressed or behave in a way which is considered inappropriate. This may be more likely at moderate to severe stages of dementia. Bear in mind that each person experiences dementia differently.

The tools provided offer a structure for running a reflective debriefing session and how to review the care provided when the resident has died (death audit). The death audit tool enables staff to review what worked well and what were the challenges for each death in the care home, and therefore helps with quality improvement.

## **ACTION**

- Commence monthly reflective debriefing sessions with staff and complete death audit tool

## **TOOLS**

- Reflective Debriefing Tool
- Death Audit Tool

## Background for the facilitator

Following the death of a resident, the immediate concern is for the bereaved family and close friends. They need to be given the time to sit with the person who has died and, when ready, given information regarding how to register the death. Be aware that some family members or close friends may want to be involved with washing the body after their relative has died. Every person – including staff – reacts to a death differently. Often adult children (especially those who don't have support from other friends or family) who have been particularly close to their mother or father who has just died need particular support; this is especially so if they were involved in the care prior to admission to the care home.

Care home staff must feel confident in knowing how to deal with a situation after a resident has died. Allowing a resident who had become a close friend with the deceased to see the body can be very helpful especially if the resident has a degree of dementia. Telling a resident with dementia that someone has died may not be remembered – however, telling them and then escorting them to see the body, if that is possible and something they would like to do, will help them understand and remember what you are saying.

Telling **other residents and staff** about the death, especially those who have been close to the person who has died, is very important. Sometimes the family themselves might want to speak to residents who they know or they might ask the staff to do it. There may be too many residents for everyone to be informed. In some care homes, the manager organises for a picture of the resident who has died to be placed on a special table in the foyer of the care home with a single flower beside it. This helps everyone coming into the care home to know that someone has died. Residents should not find out that another resident has died by reading it in the local newspaper.

**Reflecting** with colleagues following a resident's death can provide an opportunity for better support, communication and for enhancing experienced-based learning. There is a video of a 'Reflective Debriefing Session', which provides a practical guide on how this session should be facilitated (resource video three). These sessions are best organised on a monthly basis to discuss the residents who have died. Sometimes, someone from a local specialist palliative care team and other services can help with leading the Reflective Debriefing sessions, which can also build relationships.

The resident's case notes need to be respectfully completed. The Death Audit Tool can be undertaken either immediately after the death or at the monthly Reflective Debriefing Session.

## Barriers and solutions

Potential barriers to giving good care after a death in the home	Solutions
All families of residents who die in the care home are expecting it as the resident is 'old' so why all the fuss	Some family members may be more affected by the death of a relative than they thought. Giving them advice about some of the feelings they might feel (such as anxiety, disorientation, and sadness) can be very helpful.
As staff we do not need support – it's part of the work we do	Caring for dying residents and their families can be emotionally draining especially for less experienced care workers. To be able to reflect on the death of a resident together not only helps support the caring team but also is an opportunity for practice-based learning. It enables team members to think through what they might do differently next time a resident dies.
We hold the Reflective Debriefing sessions every month but sometimes there is no death	If there has not been a death in the care home during the month then use the slot planned for the Reflective Debriefing session to teach informally about an aspect of palliative care relevant to your care home.
We should not let other residents in the care home know that a resident has died	Sensitively speaking about a death to residents can help them realise that when they die their own death will be dealt with in a dignified way.

## Training session: Care after death

### Learning objectives

- To organise the dates/time for the Reflective Debriefing sessions.
- To understand how to use the reflective debriefing tool in practice.
- Ensure the Death Audit Tool is completed and up-to-date.
- To support care home staff to reflect on the deaths that have occurred in the care home during the month.
- To encourage participation and attendance by care home staff.



## Preparation

Reflective debriefings give an opportunity for staff to talk about their feelings and thoughts about the death of a resident [8]. The debriefing has two purposes; firstly, it allows care staff to discuss what they felt went well and what could be improved in future. Secondly, it increases communication across the team. Care staff should also be proactively encouraged to attend and participate in the reflective debriefing sessions, if they would like to. It is important that the reflective debriefing is held in a private, quiet room so that those attending can feel comfortable and speak openly.

There are five sections to the reflective debriefing tool:

- 1. Describe the person/event.** The introductory section allows staff to talk about the resident and paint a pen picture of who they were and their life, before admission and within the care home.
- 2. What happened leading up to the death/event?** This is an opportunity for care staff to talk about the resident's experience the month before death, and their preferences. Care staff may talk about whether they feel preferences were upheld, or their thoughts on how they knew the resident was approaching end of life.
- 3. How do staff feel things went? What went well? What didn't go so well? How did people feel?** The next section allows staff to reflect on the resident's end of life care, and explore what they felt went well, what didn't go well and how that made them feel. It is important to be honest and to respect others feelings. Care staff may feel sad, disappointed, angry or frustrated; all of which are normal reactions to death. Remember to discuss activities after death, such as contact with the resident's family.
- 4. What could have been done differently?** This is an opportunity for care staff to talk about what could have been done differently.
- 5. What do we need to change as a result of this reflection? At the end of the debriefing.** Key learning points can be decided on and any action plans documented for the future.

### Suggestions for the reflective debriefing:

- Try to ensure that opportunities for reflective debriefing are scheduled on a monthly basis.
- Identify someone to keep a record of any changes in practice that arise from the reflective debriefing.
- Remember that every staff member involved in the care home is involved in providing care. Any staff member can attend a reflective debriefing, regardless of their role within the care home.
- Ensure that the Death Audit Tool is available and can be completed, if not completed immediately after the death.

## **Resources**

Resource Video Three: 'Reflective Debriefing Session'

## Reflective debriefing tool

Initial of resident: JB

Date of reflection: 15/11/2018

Reflective debriefing is the process whereby clinical practice can be re-examined to foster the development of critical thinking and learning for improved practice. The process is on-going with each debriefing and should be viewed as an aid to lifelong learning rather than a single processes.

### 1. Describe the person/event.

For no more than five minutes, encourage all staff to recall their memory about the person or event – such as:

- Person: What were they like, what did they like to do? Did they have family? Who was important to them? What did they like/dislike? Were they humorous/serious/sad/angry? What was their perspective on what was happening? Did they have fears/anxieties?
- Event: What was the event? Who was involved?

### 2. What happened leading up to the death/event?

Describe what happened for individuals on the various shifts that led up to the death/event

### 3. How do staff feel things went? What went well? What didn't go so well? How did people feel?

Both positive and negative feelings should be described and owned. Feelings can be a useful guide to how learning is progressing so whilst it is important to be honest it is also important to respect other peoples feelings. Look at the decisions that were made – this will help you to understand what else could/could not have been done. Opinions of others will help this process. Remember to reflect on what was hoped and planned for, the original aims and objectives i.e. in the event of death in the care home:

- Was the Documentation for the Assessment/Management of the Last Days used?
- Were anticipatory drugs in place?
- Were symptoms controlled?
- Were family supported and informed?
- Were spiritual needs addressed?
- Were they in the place of their choice?
- Was a decision made that cardio-pulmonary resuscitation was inappropriate if heart stopped suddenly?
- Was an advance care plan completed?

### 4. What could have been done differently?

Existing knowledge can be built on by theorising about what could have been done differently. In order for this to be effective critical thinking in a safe learning environment is essential with a 'no blame' attitude.

### 5. What do we need to change as a result of this reflection?

Key learning points can be listed and any action plans needed to enhance learning/more appropriate care. This might be a change in or re-writing of a policy, further chats with GP/nurse specialist to ensure that in the future the problem being discussed does not occur again, or it may highlight a need for training. It is essential that these learning points are not just logged but acted on.

Each reflection can inform practice and should be used not only as a building block to learning but as a celebration of good practice. Reflection is not a passive contemplation but an active, deliberate process that requires commitment, energy and a willingness to learn as a team.

### 1. Pen portrait of person or event

John had been in the care home for about a year, and was close to his daughter and granddaughter who visited often. He liked to talk to other residents, and would talk about his time in the war with staff members. John was aware he was coming to the end of his life but seemed relaxed and calm until the end. He had pain in his shoulder, which was managed with ibuprofen, and showed signs of confusion at times.

### 2. What happened leading up to the death?

John had a chest infection at the beginning of November that was initially treated with antibiotics with little effect. Dr Patel was called out as the infection got worse and became Pneumonia, a week before death. John seemed to be improving, but declined rapidly within a 24-hour period. John's family were informed the night before his death, and he died in the care home the next morning with his daughter and granddaughter present.

### 3b. What didn't go so well?

Although John's family were in contact often, the decline in the last twenty-four hours was sudden and John's daughter was not informed of the decline until late in the night after out of hours had been called. This led to a rush to organise family members to get to the care home, causing distress for care staff and the family.

### 3a. How do staff feel things went? What went well?

John stayed in the care home until death, which were his preferences, and his pain was managed well. As much of the paperwork was already in place prior to end of life, there were no decisions to be made regarding place of care or advanced care wishes.

### 4. What could we have been done differently?

We could have called the family as soon as out of hours were contacted and monitored John's health.

### 5. What do we need to change as a result of this reflection?

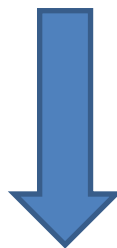
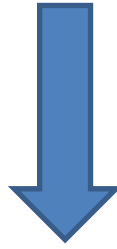
In future, we could ask families how soon they could get to the care home in an emergency.

## Data to be collected from records following a death of a resident in the care home

Initials	Gender	DOA <sup>1</sup>	DOD <sup>2</sup>	Current diagnoses	DNACPR ? <sup>3</sup>	Care Discussion ? <sup>4</sup>	Last days of life tool <sup>5</sup>		Hospital Admission <sup>6</sup>	Place of death <sup>7</sup>	Hospital death only <sup>8</sup>		
							Tool used?	Start date			Admission time	Person req.	Type of death <sup>9</sup>
JB	M	01/01/ 2018	11/11/ 2018	Mild dementia, skin cancer, generalised frailty	Yes	Yes	Yes	01/11/ 2018	N	Care home	NA	NA	D

### Guidance Notes:

1. Date of admission
2. Date of death
3. Documented evidence of DNACPR?
4. Documented evidence of future care discussion?
5. Use of tool for last days of life and date tool commenced
6. Number of hospital admissions in last month of life
7. Place of death: care home, hospice, hospital (if recently discharged from hospital state no. of days prior to death)
8. Hospital death only: please complete time of admission and who requested admission
9. D = dwindling – slow deterioration with loss of weight over a matter of weeks/months; S = sudden (i.e. heart attack in dining room; or found dead in bed at night); A = after ‘acute’ episode – ‘unexpected death’ with deterioration over a few days (i.e. extension of stroke; fractured femur); T = diagnosed terminal condition – cancer, Parkinson’s.



1. Pre portrait of person or event	2. What happened leading up to the death?
3a. What didn't go so well?	3b. How do staff feel things went? What went well?
4. What could we have been done differently?	5. What do we need to change as a result of this reflection?



# Keeping it going

## KEEPING THE PACE STEPS TO SUCCESS PROGRAMME GOING

### Objectives during the 'Keeping it going' stage (4 months)

- Develop a team approach to the provision of high quality palliative care for residents.
- All new staff employed in the care home are introduced to, and involved with, the PACE Steps to Success Programme to improve and enhance palliative care.
- Encourage a culture that supports open communication about death and dying in the care home.
- Make sure that staff are using the right documents to assess pain.
- Arrange the two 'monthly' meetings; namely, the multi-disciplinary palliative care review meetings; and the reflective debriefing sessions following the death of a resident.

After the initial implementation of the PACE Steps to Success Programme, it is important that the momentum continues by pre-planning dates and times for the monthly palliative care meetings and staff reflective debriefing sessions. The PACE programme should be introduced to any new members of staff so that they are familiar with it. This is a valuable opportunity to repeat aspects of the programme that require further explanation.

This 'keeping it going' period helps to establish all the Steps taken during the implementation of the PACE programme. By now you should have a good understanding of the 'PACE Steps to Success' programme. However, because of the high turnover of staff in care homes, further training on aspects of the PACE programme, such as using the 'Looking and Thinking Ahead' tool, may be required during this period to ensure all care staff are familiar with all the Steps and tools associated with the PACE programme.

Caring for frail older people is about providing a culture of palliative care that is underpinned by compassionate staff who know how to assess symptoms (whether physical or psychological) and get the help that residents need. For example, make sure that assessment charts for pain are being used for the residents who have symptoms.

## Background for the facilitator

You will have learnt a lot, and role modelled good palliative care to the rest of the staff. Hopefully through on-going *monthly multi-disciplinary palliative care review meetings*, and the *monthly reflective debriefing sessions* the rest of the care home staff are learning too and there is increased coordination of residents' care. These two 'monthly' meetings **must be embedded in the care home culture**. They provide wonderful opportunities for ongoing learning but need to be effectively led.

Finally, care home staff and families need to work together in order to provide residents with a good quality of life in the last year of life.

## Barriers and solutions

Potential barriers to sustaining the 'PACE Steps to Success' programme in the care home culture	Solutions
Cannot motivate staff to be interested in the care of residents who are dying	Palliative care needs to be regularly on the agenda of various meetings. How good quality palliative care is role modelled from the senior staff will influence how staff then care for residents and their families. If staff are not doing it, think carefully how it is being role modelled. All potential new staff to the care home need to understand that frail older people will be supported to die in the facility wherever possible.
'I cannot do it all on my own'	Of course, you cannot do it all on your own, that is exactly right! You are not expected to. The manager of the care home needs to make sure that other staff are behind you. If they are not – ask for the care home manager's help. You may need dedicated time each week.
Inadequate staffing in the care home	Good palliative care does require adequate staffing. If you feel staffing is inadequate – you need to work out why you think it is inadequate and then write to the higher management. Management often do not realise the number of residents who die and the palliative care they need.
Our doctor is not involved	Medical input into care homes is really important – it helps to build relationships over time. Sometimes reminding doctors that the meetings planned as part of the programme do require more time but hopefully will save time too.



## GLOSSARY

**These definitions refer to the UK; if you work elsewhere check your local definitions**

***Advance decision to refuse treatment.*** This must be in writing if it relates to life sustaining treatment, signed and witnessed and is legally binding. This might also be known as a Living Will.

***Lasting Power of Attorney (LPA) Property and Affairs:*** This allows a person to choose someone to make decision about how to spend another person's money and manage their property and affairs.

***Lasting Power of Attorney (LPA) Personal welfare:*** This allows a person to choose someone to make decisions about another person's healthcare and welfare. This includes decisions to refuse or consent to treatment on their behalf. These decisions can only be taken on a person's behalf when they lack the capacity to make the decisions themselves and must be taken in their best interests. All LPAs **must** be registered with the Office of the Public Guardian to be valid.

## **FURTHER INFORMATION for England**

- Mental Capacity Act Code of Practice (2007) published by The Stationery Office on behalf of the Department for Constitutional Affairs. Available at:  
[www.gov.uk/government/publications/mental-capacity-act-code-of-practice](http://www.gov.uk/government/publications/mental-capacity-act-code-of-practice)
- Chapman S (2008) The Mental Capacity Act in Practice: Guidance for End of Life Care. London; National Council for Palliative Care.
- Social Care Institute for Excellence (2015) Mental Capacity Act (MCA) Directory  
[www.scie.org.uk/mca-directory/making-decisions/](http://www.scie.org.uk/mca-directory/making-decisions/)
- Regnard C (2012) Deciding Right; An integrated approach to making care decisions in advance with children, young people and adults.
- End of Life Care Programme (2008) Advance Care Planning: A Guide for Health and Social Care Staff. [www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf](http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf)

## **RESOURCE VIDEOS**

All videos are available on the EAPC website.

1. Resource Video One: What is Palliative Care?
2. Resource Video Two: Role model of a 'Monthly Palliative Care Review Meeting
3. Resource Video Three: 'Reflective Debriefing Session'

## REFERENCES

1. Department of Health, The route to success in end of life care - achieving quality in care homes. 2010.
2. The Gold Standards Framework for Care Homes, 2018 The GSF Care Homes Training programme. National Gold Standards Framework Centre. Accessed at [www.goldstandardsframework.org.uk/care-homes-training-programme](http://www.goldstandardsframework.org.uk/care-homes-training-programme)
3. Macmillan Cancer Support. Foundations in Palliative Care, 2018. Macmillan Cancer Support. Accessed at <https://learnzone.org.uk/courses/course.php?id=318>
4. European Association of Palliative Care. EAPC Publications, 2018. European Association of Palliative Care. Accessed at [www.eapcnet.eu/Themes/AbouttheEAPC/DefinitionandAims.aspx](http://www.eapcnet.eu/Themes/AbouttheEAPC/DefinitionandAims.aspx)
5. World Health Organization, WHO Analgesic Ladder, 2013, a lecture by Michelle Munro from the Ghana Emergency Medicine <http://www.slideshare.net/openmichigan/2013-gemcnursingmunroadmin-managementofpainmedsoer>
6. Clark D, 'Total pain': the work of Cicely Saunders and the maturing of a concept. 2014, End of Life Care Studies: University of Glasgow.
7. Volicer L and Hurley A, Assessment scales for advanced dementia. 2015, Baltimore, MD: Health Professions Press.
8. Hockley J, Intimations of Dying: a visible and invisible process. *Journal of Palliative Care*, 2015, 31 (3): pp.166-71.
9. Hockley J, Learning, support and communication for staff in care homes: outcomes of reflective debriefing groups in two care homes to enhance care *International Journal of Older People Nursing*, 2014. 9(2): pp.118-30