Special edition

My home life

Promoting quality of life in the care home sector

Step by step guide

The route to success in end of life care

What is *My* Home Life?

My **Home Life** is a UK-wide programme aimed at promoting quality of life for older people living and dying in care homes and for those visiting and working with them, through relationship-centred care and evidence-based practice.

Led by the care home sector itself in partnership with Age UK, City University and Joseph Rowntree Foundation, ***My*** **Home Life** is a movement for change, celebrating all that is positive in care homes and providing the vision for practice in care homes in the 21st Century.

This bulletin has been developed in conjunction with the **NHS National End of Life Care Programme**, who are developing a series of route to success documents for different care settings.

The aim of the *National End of Life Care Programme* is to bring about a step change in access to high quality care for all people approaching the end of life. High quality care should be available wherever the person may be: at home, in a care home, in hospital, a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.' (Ref EoLC Strategy, 1.33, p33)

This guide is being distributed to 18,000 care homes on behalf of ***My*** **Home Life** through Care Management Matters. Additional copies can be provided at a cost of £1 per issue (+ 50p towards p&p) from AgeUK Publishing (tel. 020 7278 1114).

Introduction

"Many of the residents in this home have no more than days or weeks to live and appreciate the time, patience, care and expertise of staff to help them cope with the journey to death."

My **Home Life** have heard many positive stories that demonstrate that care homes have definitely responded to the challenge of providing quality of life right up to the end. Practices have greatly improved over the years. However, delivering good end of life care can often feel daunting, it can create anxiety among staff, residents and relatives alike. It can feel like yet another area of practice where we don't have enough time to develop our skills and expertise.

This bulletin aims to provide managers and staff with a simple guide to support the implementation of an end of life care 'pathway'. The bulletin follows the six steps of the pathway from the ***National End of Life Care Strategy***, and includes questions to ask about the resident's care and the staff's role in that care.

The option for using other additional helpful resources is signposted at the end of this bulletin.

We all know that pathways, while useful, are just a starting point. But whether your residents are at the end of life or not, the real challenge is to create a culture where your staff, residents and relatives have positive relationships with one another. This is at the heart of quality of life and key to a quality of end of life.

"Care homes are increasingly at the forefront of good practice in providing care for those who are approaching or reaching the end of their life."

From all of us associated with the *My* Home Life **initiative, keep up the good work!**

Step 1.
Discussions
as the end of life approaches

Enabling residents to die in comfort and with dignity is a core function of care homes. One of the key challenges for managers and staff is knowing how and when to open up a discussion with individual residents (and relatives) about what they would wish for as they near the end of life. Agreement needs to be reached on when discussions should occur, who should initiate them and what skills and competences staff require to take on this role.

Questions

- Can you identify those in your care who are approaching end of life?
- Have you noted triggers which might indicate it is an appropriate time for discussion?
- Are you certain you know whether a resident does or does not wish to have a conversation about their future care?

Your role

Recognise when an resident's signs and symptoms have increased or condition has deteriorated.

Ask yourself, "Would you be surprised if this resident were to die at sometime in the near future".

Identify those who need to be receiving end of life supportive care.

Remember to take into account triggers, such as recent changes in circumstances. This could be the death of a spouse, increased hospital admissions or a change in care setting e.g. a move from residential to a nursing home.

Identify whether it is appropriate to open a supportive discussion with the resident and/

"It can be very difficult to predict when a resident is going to die. We tend to try to find informal and supportive ways to broach the subject with each and every one of them if possible. Sometimes this is about picking up on a comment or remark made by the resident about their mortality, and using this as an entry point to further discussion."

or their family about their wishes for end of life and the best time or circumstances to do that.

Consider carefully whether the individual wishes to have open discussions about prognosis and possible future care options.

Provide any relevant information which may be required by the resident or their family.

Top Tip

Recognise that greater attention and support may be required for those residents who struggle to communicate their needs because of dementia or other health problems.

Step 2.

Assessment

care planning and review

"One of the key challenges that we have is when there is a conflict between a resident's wishes and what a relative feels they would like to happen at the end of life. Building strong relationships with the relatives from the start can really help when we try to resolve these situations."

An early assessment of a resident's needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as identifying any areas of unmet need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each resident.

Questions

- Does your care plan assessment include an exploration of all aspects of end of life care (social, emotional and spiritual) as well as physical?
- Do you feel sufficiently confident and skilled in supporting residents to identify their wishes and preferences about their future care? Might additional training and support be valuable?
- Have the wishes or concerns of the relatives or advocates been considered?
- Have you considered how you might gather information from or about those of your residents that struggle to communicate, perhaps because of dementia or stroke?

Your role

Undertake a holistic assessment for end of life needs and preferences in partnership with your residents and, where appropriate, their relatives and friends.

Assess and respond sensitively to the social, psychological and spiritual needs and wishes of a resident as well as their physical care needs.

If necessary support an assessment of the resident's ability to make decisions about their care (guidance provided in the Mental Capacity Act 2005 Code of Practice).

Identify, record and respond to an resident's personal wishes and preferences about their

future care and implement regular reviews (Advance Care Planning) and verify this with their local GP if necessary.

If requested you should support a resident in the recording of an Advance Decisions to Refuse treatment document in an appropriate format (guidance provided in the Mental Capacity Act 2005 Code of Practice).

Communicate information about personal wishes and preferences (with permission) to relevant people e.g. GP, Out of Hours Service

Did you know?....

If residents make an advance decision to refuse life sustaining treatment it must be in writing, signed by the person (or representative) and witnessed.

Step 3. Co-ordination of care

Once a care plan has been agreed it is important that all the services the resident needs are effectively coordinated. A lack of coordination can mean the resident's needs and preferences are not met.

Questions

- Is there a communication system in place to keep all members of the care home team and others outside of the home (relatives, friends, health professionals) fully informed of the end of life care plan?

- Has a key worker been identified within the home who can develop a strong working relationship with those key professionals who may be needed in order to meet the end of life care plan?

- Are systems in place for services to respond rapidly and appropriately, (out of hours as well as working hours), to changes in circumstances as end of life approached? For example, anticipatory drug prescribing and access to special equipment.

Your role

Ensure local healthcare professionals are aware of those approaching end of life. Some GP practices may be implementing an end of life care register.

Make sure good communication systems are in place with all relevant services.

Ensure you know who your key contacts are across the provider services, voluntary bodies and social care sectors.

"Friendship and teamwork in a home can help with good quality end of life care, because success is often all about integration and linking up with colleagues."

Make sure there is a key worker within the home for the individual approaching end of life, who can also act as the link between services.

Ensure timely access to relevant equipment and drugs which may be required is possible.

Inform Out of Hours Services of anticipated care needs.

Inform ambulance services of anticipated care needs.

Top Tip

Find out which pharmacies your local hospice use, these are more likely to offer an out-of-hour delivery of medication.

Step 4.
Delivery
of high quality services in different settings

"Our local council offer a forum where we can talk openly with GPs, staff from the local hospital and the end of life care teams, about all kinds of issues including end of life care. It really helps to put a face to a name, and means that I can pick up the phone to any of them if I need some advice or to talk about a residents needs."

Residents and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of whether they are living independently at home or in a care home.

Questions

- Has a policy for the management of end of life care been developed within your organisation? i.e What to do in various end of life scenarios? For example, weekend or middle of the night situations.
- Can all staff access any internal or external ongoing training and support programme for end of life care?
- Does the environment within the care home offer privacy, dignity and respect for individuals and their families as end of life approaches?
- What systems are in place to monitor and evaluate the quality and delivery of end of life care?
- Can you ensure that any transition from the care home to a hospital is well coordinated and minimises any distress for your resident?

Your role

Establish or be aware of the operational policy for implementing end of life care in your care home.

Ensure you have awareness and understanding of end of life care core principles and values.

Promote or participate in the different aspects of end of life care training which may be available to you. There is no one set format for the delivery of training.

Where possible access training around communication skills, assessment and care planning, advance care planning, symptom management and comfort and well-being.

Give consideration to the environment in which end of life care and support is delivered, for example, is there access to a quiet room or facilities for relatives.

Use relative, staff, or advocate experiences to help provide constructive feedback to support continuous practice improvement.

Top Tip

Don't forget the role that other residents, particularly those who have developed a close relationship with the person who is dying, may be able to play in the planning and delivery of care.

Step 5.
Care
in the last days of life

The point comes when a resident enters the dying phase. It is vital that staff should recognise that this person is dying and take the appropriate action. How someone dies remains a lasting memory for the resident's relatives, friends and the care staff involved.

Questions

- Are you aware of the changes which may occur with an residents's condition during the dying phase?
- Are systems in place for involving families and friends in some aspect of the care-giving or in discussions as death approaches?
- Have any specific wishes or preferences been identified by the resident for this time?
- Has the Liverpool Care Pathway for Care Homes (LCP) or other equivalent pathway been implemented?
- Have you responded to any particular spiritual or cultural needs that have been recorded as part of the end of life planning?

Your role

Be aware of the processes which occur during the last days of life and be alert to the possibility that on occasions an resident's condition may improve.

Have open discussions with relatives, friends and other members of staff to ensure you all know what to expect during the last days of life, and offer support where needed.

After training in the use of the Liverpool Care Pathway, staff feel confident in discussing issues about dying, and are better placed to make appropriate preparation when a resident's condition begins to deteriorate.

Where possible adhere to an resident's stated wishes and preferences

If a person lacks mental capacity, try to identify what they would take into account, if they could make their own decisions

With appropriate training, follow a 'validated integrated care pathway' for the last days of life such as the Liverpool Care Pathway.

Where possible have anticipatory prescribing systems in place or a system for rapid access to necessary medication.

Anticipate and be prepared for any specific religious, spiritual or cultural needs a resident might require.

Step 6. Care after death

Good end of life care doesn't stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support and care provided to relatives will help them cope with their loss and is essential to achieving a 'good death'. This is important too for staff, many of whom will have become emotionally connected with the resident.

Questions

- Have the relatives been provided with appropriate support information?
- Are systems in place for advising on or offering bereavement support?
- Do mechanisms exist to support non-family members, such as staff, other residents and friends, who may also be affected by a death?

Your role

Respect individual faiths and beliefs and take steps to meet their requirements.

Be aware of verification and certification of death policies.

Provide appropriate information to relatives and carers about what to do after a death.

Offer information about bereavement support services if required.

Provide a comfortable environment in which staff and, where appropriate, other residents, can discuss or share their feelings.

Provide staff, residents and relatives with the opportunity for remembrance and showing their respect.

"Residents are remembered through a memory book of poems and photos. We have also created a memorial garden with trees planted to remember those who died."

What next

Share this information with all staff who may be involved in the delivery of end of life care.

- Find out if there is any available training in your area.
- Log onto available resources www.myhomelife.org.uk
- For specific resources relating to the Route to Success care programme visit www.endoflifecare.nhs.uk/routes_to_success/

Coming soon from *My* Home Life…

Over the next 18 months, a series of practical bulletins will be produced, bringing together your examples and stories of good practice along with top-tips to help you promote quality of life in your care home. These will be sent to you through Care Management Matters, as well as being available on our new website.

The ***My*** Home Life team is getting out and about across the country, gathering and sharing good practice and reminding the wider community that care homes can be a very positive option for many older people.

We are building on the substantial energy, expertise and commitment across the care home sector, to grow a powerful movement for improved quality of life.

Please keep sending us your stories of how you have improved the quality of life for your residents, relatives and staff, and join the network so that we can keep in touch.

Best Wishes

The ***My*** Home Life team

My Home Life is a UK-wide initiative that promotes quality of life and delivers positive change in care homes for older people. We work with care homes, statutory bodies, community organisations and others to co-create new ways of working to better meet the needs of older people, their relatives and staff. Our vision is a world where care homes are great places to live, die, visit and work; where care homes are:

- Supported to deliver to their potential
- Valued and trusted by those who work with them
- Cherished by their local communities

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