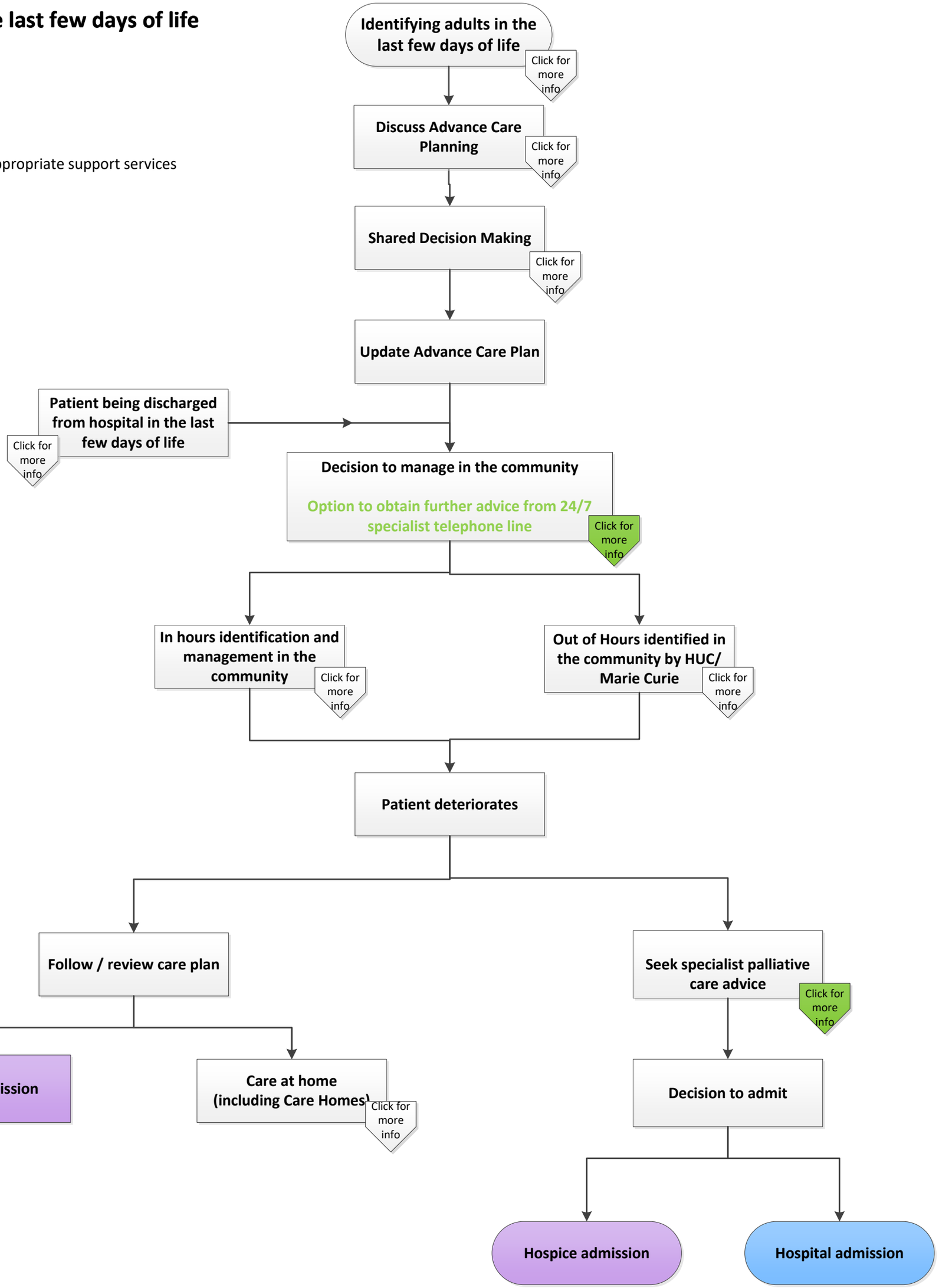
Management of adults in the last few days of life

Considerations after Death

- Bereavement needs/signposting to appropriate support services
- Consider organ donation
- Post Death Audit (PDA)

Click for pharmacy info

Click for info for carers, relatives & patients



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Identifying adults in the last few days of life

- Clinical judgement must be applied including assessing for changes in signs and symptoms in the person and any investigations that may suggest a person is entering the last days of life. These changes may include:
  - agitation
  - Cheyne–Stokes breathing
  - deterioration in level of consciousness
  - mottled skin
  - noisy respiratory secretions
  - progressive weight loss
  - increasing fatigue
  - loss of appetite
  - functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering.

Avoid undertaking investigations that are unlikely to affect care in the last few days of life unless there is a clinical need to do so.

Use the knowledge gained from the assessments and other information gathered from the multi professional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving.

Monitor for further changes in the person at least every 24 hours and update the person's care plan.

Seek advice from colleagues with more experience of providing end of life care when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

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Advance Care Planning

- Does a ACP already exist and does it need updating?
- If no previous discussions have taken place explore with the dying person and those important to them: whether the dying person has an advance statement or has stated preferences about their care in the last days of life.

Priority ACP areas to be recorded and regularly reviewed include:
- Preferred Place of Care
- Preferred Place of Death
- Escalation plan/ crisis management for when the patient's condition deteriorates (for example: do not readmit to hospital) or social circumstances change
- Consider the following:
  - Just in case guidance
  - Just in case medication
  - Just in case syringe driver
  - Consider DNACPR
- Carers needs

Ensure ACP is shared with healthcare professionals generally - obtain consent from patient if not already done.

Ensure GP and GSF Co-ordinator is aware an ACP is now in place.

Communicate with relatives and carers

Establish the communication needs and expectations of people who may be entering their last days of life, taking into account:
• if they would like a person important to them to be present when making decisions about their care
• their current level of understanding that they may be nearing death
• their cognitive status and if they have any specific speech, language or other communication needs
• how much information they would like to have about their prognosis
• any cultural, religious, social or spiritual needs or preferences
•Identify the most appropriate available multi professional team member to explain the dying person's prognosis.
Base this decision on the professional's:
•competence and confidence
•rapport with the person

Discuss the dying person's prognosis with them (unless they do not with to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.
Provide the dying person, and those important to them, with:
*accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
*an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
*information about how to contact members of their care team
*opportunities for further discussion with a member of their care team.

Explore with the dying person and those important to them:
*Whether the dying person has an advance statement or has stated preferences about their care in the last few days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
*Whether the dying person has understood and can retain the information given about their prognosis. Discuss the dying person's prognosis with other members of the multi professional care team and ensure that this is documented in the dying person's record of care.

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Shared decision making

Establish the level of involvement that the dying person wishes to have and is able to have in shared decision-making, and ensure that honesty and transparency are used when discussing the development and implementation of their care plan **consider mental capacity, also check for lasting power of attorney for health and wellbeing**.

Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life. Providing individualised care.

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Patient being discharged from hospital in the last few days of life

Minimum standards:

- Acute Trust to complete/update ACP/ Individual Care Plan for the Dying Person (ICPFDP) with patient if not already in place or up to date and ensure a copy accompanies the patient
- Ensure original signed DNACPR is completed and given to patient on discharge, if appropriate
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- Ensure adequate information is provided to the GP as part of the discharge summary
- Discharged with medication
- Ensure relevant Fastrack paperwork is complete and placement/POC is available (including any equipment and social care needs)
- Ensure all clinicians are aware of discharge

N.B. If a patient wishes to be discharged before a Fastrack placement/POC is in place, the Care Co-ordinator/Social Services needs to be informed **ON DAY OF DISCHARGE**, in order that they can:

(a) ensure care is put in place and

(b) continue to progress the Fastrack

- Trust to update GP/HUC/DN

Where possible verbally communicate with primary care / community providers re: discharge plan and patient wishes

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Obtain further advice from 24/7 specialist telephone line

Daytime advice:
Isabel Hospice - 01707 382 575
Garden House Hospice – 01462 416 794
East & North Herts SPC Team – 01462 427034
Keech Hospice - 01582 492339
St Clare Hospice - 01279 773773
Luton Community SPC - 0333 405 3000

Out of Hours Specialist Palliative Care Advice Lines:
East Herts – 01707 382575
North Herts – 01462 416794
St Clare Hospice - 01279 773773 (24 hour advice line)

Current Service Specification – Hospices:
The telephone advice lines provide 24 hour telephone contact support and deliver specialist palliative care (SPC) advice and support to service users, carers and health and social care professionals.

This care and support includes:

- Access to a registered nurse and a Doctor for telephone assessment and review at any time of day or night as required by any caller.
- Advice and support relating to symptom control, treatment and management.
- Advice and support relating to psychological care – dealing with the emotional implications of illness, including stress and depression.

Where possible and appropriate, care and support may include:

- Advice and support relating to social care – caring for the service user and supporting their family or carers to cope with the experience of illness.

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Ambulance called - patient in last few days of life

- EEAST called
- Check patient held documentation. Follow if available.
- If no CPFDP/ DNACPR/ACR make a clinical decision with patient and their relatives on care preferences
- Support services available through SPC telephone advise line (24/7) and SPC Dr/Nurse available 9am-5pm for face to face visit
- Consider urgency of situation:
- If patient has deteriorated but not in last few days call 111 for further help and support or consider hospice admission depending on preferred place of death wishes
- If patient identified in last few days call 111/GP to start a joint care plan for the last few days of life (Individual Care Plan For the Dying Patient) if appropriate
- Admit to hospital if in line with patient wishes
- Communicate with patient/ relative where appropriate

Ensure Care Co-ordinator and GP are informed following visit and/or contact DN for support if patient staying at home

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Support to relatives and carers

- Ensure patients and carers have all relevant contact information
- Ensure relatives and carers contact details are up to date
- Ensure patients and carers understand how to access support at every stage
- Acknowledge carers, what they do, and the problems they have.
- Treat carers as you would other team members and listen to their opinions.
- Include them in discussions about the person they care for.
- Give carers a choice about which tasks they are prepared to take upon themselves.
- Ask after the health and welfare of the carer as well as the patient.
- Provide information about the condition the person the carer is looking after suffers from.

Carers' assessment and support is a crucial area and is one of the most important aspects of the care provided by primary healthcare teams.

Carer breakdown is a key factor in prompting institutionalised care for dying patients.

For further information on supporting carers, see: http://www.rcgp.org.uk/clinical-and-research/a-to-z-clinical-resources/carerssupport.aspx

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Health Care Professional identifies patient in last few days of life and carries out the following actions:

- Escalate to named Care Co-ordinator AND/OR GP straight away
- Care Co-ordinator/GP discussion:
- Consider home visit
- Consider who will complete the care plan for the last few days of life (Individual Care Plan for the Dying Patient - ICPFDP) - usually community nursing or palliative care and jointly with GP
- Jointly agree and activate a plan for the last few days of life (community nursing/palliative care plan needs to be signed of by a doctor - usually the GP).
- Care plan will be documented by the community team using the agreed SystmOne End of Life template EPaCCS (EoL template). This will be shared (if patient consents). SystmOne GPs will be able to view the full record and EMIS GPs will be notified and should be sent a downloaded copy of the plan
- Contact relevant service where appropriate e.g. DN, Carers, HES
- Consider patient held documentation
- Preferred Priorities for Care Document (PPC)
- DNACPR

Support services available through SPC telephone advise line (24/7) and SPC Dr/Nurse. Available 9am-5pm for face to face visit if appropriate.

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Out of Hours identified in the community by HUC/ Marie Curie

- 111 called
- OOH GP to locate patient held documentation e.g. Advanced Care Plan (ACP)/ DNACPR and review/update as appropriate
- If patient not on Individual Care Plan for the Dying Patient (ICPFDP) consider urgency of situation and
  (a) manage as is or
  (b) consider ICPFDP
- Communicate with patient/relative where appropriate
- Ensure Care Co-ordinator and GP are informed following visit
- Consider patient held documentation:
  - Preferred Priorities for Care Document (PPC)
  - DNACPR

Support services available through SPC telephone advise line (24/7) and SPC Dr/Nurse available 9am-5pm for face to face visit

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Identify resources to support patient needs/ Care at home (including Care Homes)

Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.

In discussion with the dying person, those important to them and the multi-professional team, create an individualised care plan.
The plan should include the dying person's: personal goals and wishes, preferred care setting, current and anticipated care needs including: preferences for symptom management, needs for care after death, if any are specified resource needs.

Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multi-professional care team.

Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.

Support to relatives and carers

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- Ensure patients and carers understand how to access support at every stage
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Support for Carers

Carers Trust: http://www.carers.org/

RCGP Carers support: http://www.rcgp.org.uk/clinical-and-research/a-to-z-clinical-resources/carers-support.aspx

Help with bereavement: http://www.nhs.uk/Livewell/bereavement/Pages/bereavement.aspx

Cruse Bereavement Care: http://www.cruse.org.uk/

Marie Curie Bereavement Support: https://www.mariecurie.org.uk/help/bereaved-family-friends

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Pharmacy information

- Just in case guidance
- Just in case medication
- Just in case syringe driver
- Downloadable templates available
- Palliative Care Medicines - Participating Pharmacy details are available

Link to all: http://www.enhertsccg.nhs.uk/eolc-templates

Pathway references

NICE guidance 'Care of dying adults in the last days of life' Overview | Care of dying adults in the last days of life | Guidance | NICE

Treatment and care towards the end of life: good practice in decision making' https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life