Summary End of Life Care Map – Adults

NB: This pathway is a summary of last year of life & links to other End of Life pathways.

GMC End of life Definition: Patients are 'approaching the end of life' when they are likely to die within the **next 12 months**. This includes patients whose death is imminent (expected within a few hours or days) and those with:

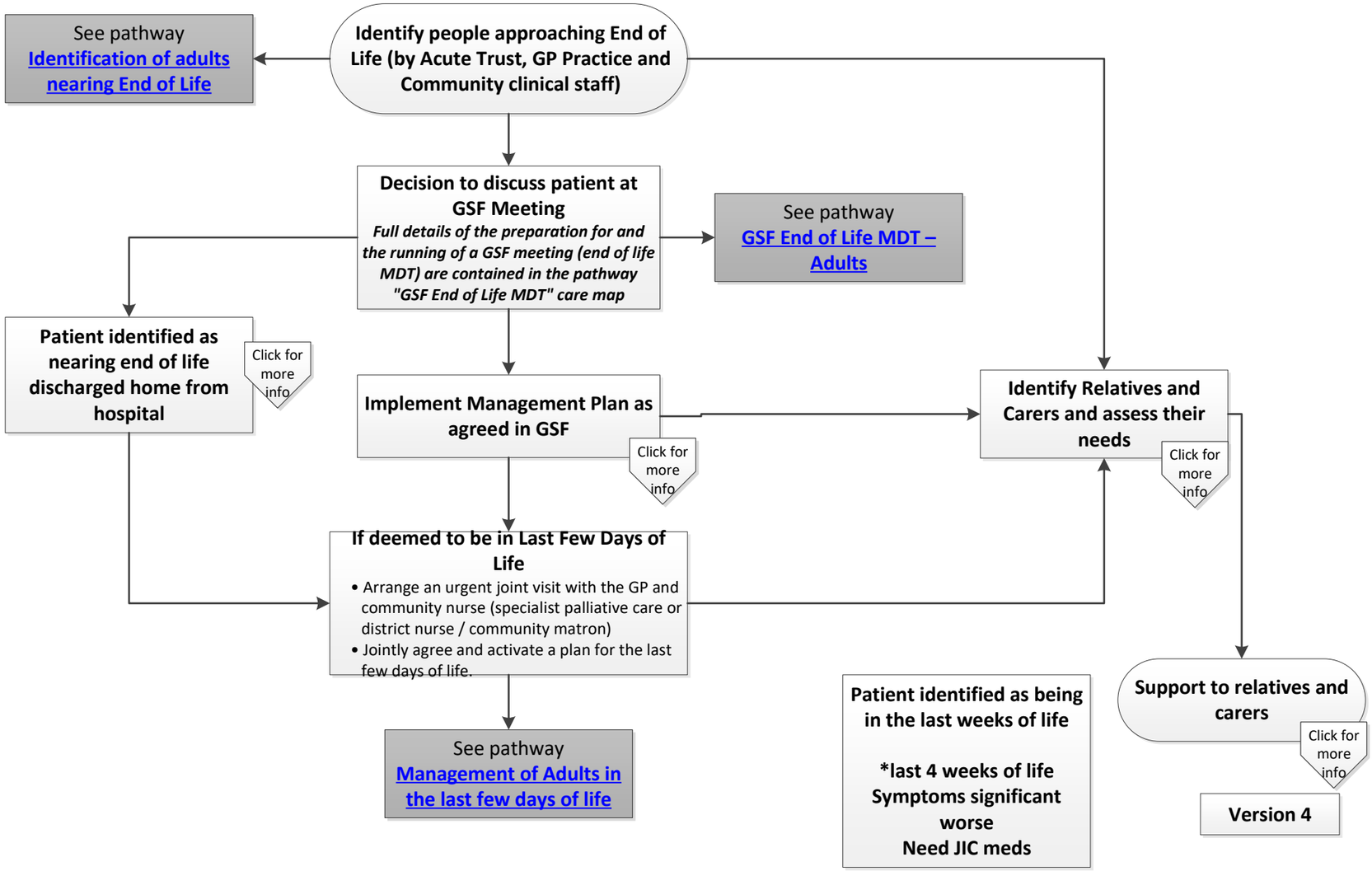
(a) advanced, progressive, incurable conditions;
(b) general frailty and co-existing conditions that mean they are expected to die within 12 months;
(c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition and
(d) life-threatening acute conditions caused by sudden catastrophic events.

Considerations after Death

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

Click for further info for GPs

Click for info for carers / patients / relatives



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Patient identified as nearing end of life discharged home from hospital

Minimum standards:

- Acute Trust to complete/update ACP/ Individual Care Plan for the Dying Person (ICPFDP) with patient and communicate this information on discharge so that the EoL Template can be updated
- Ensure original signed DNACPR is completed and given to patient on discharge, if appropriate
- Ensure adequate information is provided to the GP as part of the discharge summary
- Discharged with 14 days of medication
- Ensure relevant Fastrack paperwork is complete and placement/POC is available (including any equipment and social care needs)
- N.B. If a patient wishes to be discharged before a Fastrack placement/POC is in place, CHC / 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

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Implement Management Plan as agreed in GSF

See 'GSF End of Life MDT' pathway for details of management plan decisions and referrals

Review as required

- Named care co-ordinator to ensure clinical and social management plan is enacted with reviews as required
- GSF co-ordinator to ensure patients have regular GSF reviews
- GSF co-ordinator to liaise with clinicians if patient requires an earlier review date
- Use SystmOne/EMIS EPaCCs EoL template and share record if consent given

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Identify Relatives and Carers and assess their needs

- Identify and document relatives and carers on EPaCCs SystmOne/EMIS EoL template
- Facilitate conversation between patient and carer(s) to establish if they are able to take on the carers role and what support they might need
- Ensure patients and carers have all relevant contact information
- Ensure patients and carers understand how to access support at every stage

Useful tools for assessing the needs of carers:

- Views on Care
- The Zarit Carer Interview
- Additional Carer Questions

https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/

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Support to relatives and carers

- 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.

Supporting carers in end of life care

- Acknowledge carers, what they do, and the problems they have.
- Flag the notes of informal carers so that in any consultation you are aware of their circumstances.
- 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.
- Provide information about being a carer and support available.
- Provide information about benefits available.
- Provide information about local services available for both the person being cared for and the carer.
- Be an advocate for the carer to ensure services and equipment are appropriate to the circumstances provided.
- Liaise with other services.
- Ensure staff are informed about the needs and problems of informal carers.
- Respond quickly and sympathetically to crisis situations.

For further information on supporting carers, see: https://www.mariecurie.org.uk/help/support/being-there

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Further Information for GPs

Identifying end of life patients: http://www.dyingmatters.org/gp_page/identifying-end-life-patients

NICE - Care of Dying Adults in the Last Few Days of Life: https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-

RCGP Palliative and End of Life Care Toolkit (including The GSF Prognostic Indicator Guidance): https://elearning.rcgp.org.uk/mod/book/view.php?id=12529&chapterid=270

BMJ - An introduction to advance care planning in practice: https://elearning.rcgp.org.uk/mod/book/view.php?id=12529&chapterid=270

Guidance to support advanced care planning

Gold Standard Framework: http://www.goldstandardsframework.org.uk/advance-care-planning

Planning for your future care: http://www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead.aspx

DNACPR Guidance and Documentation: https://heeoe.hee.nhs.uk/sites/default/files/dnacpr_policy_-_east_of_england_1.pdf

Hertfordshire Palliative Care 'Just In Case' Guidelines: http://www.hertslpc.org.uk/our-news/hertfordshire-palliative-care-just-in-case-guidelines/

Gold standards Framework: https://www.goldstandardsframework.org.uk/resources-2?_gl=1*aielhz*_ga*NTQ2Njg1ODYxLjE2Njk5OTY1NzM.*_ga_Z51FL7003V*MTY4Mzc5NzM0Mi4yLjEuMTY4Mzc5NzM1Ny40NS4wLjA.

Ethical Guidance:https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

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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

NHS Choices: http://www.nhs.uk/Livewell/bereavement/Pages/bereavement.aspx

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

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