

Living and Dying Well: a national action plan for palliative and end of life care in Scotland

ACTION 1: NHS Boards, through palliative care networks and CHPs, should ensure that recognised tools/triggers to support the identification of palliative and end of life care needs of patients diagnosed with a progressive, life-limiting or incurable condition and the needs of their carers are used across all care settings by 2010		<i>Action plan reference</i>	
OBJECTIVES		CHANGES / IMPROVEMENTS	
		Timescale	Responsible group or person
1.1	Develop a short tool to aid the decision when to add patients to palliative care register.	27.2.09	MCN Executive Group
1.2	Ensure patient identification tool is rolled out to all practices in Lanarkshire, readily available (electronically and on paper), and GP facilitator contacts each practice in relation to its use.	31.12.09	GP Facilitator
1.3	Develop a short paper-based tool combining PCS and care plan summary (including identification of patient + carer needs) to be completed within two weeks of inclusion on the register.	27.2.09	MCN Executive Group
1.4	Create a central resource of palliative care identification tools (including additionally GSF SCR1 summary sheet and SCR Front Sheet) that is readily available.	30.4.09	MCN Manager/Co-ordinator
1.5	Scope the potential of consultants from range of specialities advising GPs when patients reach the last year of life.	30.6.09	GP Facilitator
1.6	Provide additional education and support to care home GPs and liaison nurses to ensure all palliative care needs are identified within care homes	31.12.09	GP Facilitator
1.7	Provide rolling programme of education for staff in all care settings (including hospitals and those working in people's own homes) in relation to identification of palliative care needs.	30.09.09	GP Facilitator
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.			
<p>Family carers have no formal training/experience of palliative care triggers and can be valuable partners in the identification process if they are aware of them. The five new carer support staff may be able to assist carer needs identification. The distress thermometer may be another useful tool to aid identification of needs, particularly for carers. It would be helpful to link the practice carer register to the palliative care register, especially if a carer has palliative needs. Many family carers are frightened and distressed by palliative care and need support. The responsibility for identification of needs is not solely the GPs, but involves many other members of staff, including those responsible for deciding when the need becomes palliative.</p>			

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ACTION 2: NHS Boards, through palliative care networks and CHPs, should ensure that patients identified with palliative and end of life care needs are appropriately assessed and reviewed in all care settings using recognised tools currently available.		<i>Action plan reference</i>		
OBJECTIVES		CHANGES / IMPROVEMENTS		
Identify through stating your <u>objectives</u> in relation to this Action Point, what you are trying to accomplish . Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.		Identify the changes (improvements) you have made / planning to make , in relation to each of your stated objectives.	Timescale	Responsible group or person
2.1	Develop action plan by 30 April '09 to address LPCAT audit results, specifically aiming for comprehensive utilisation by relevant staff groups.	LPCAT developed by nurses locally. Rolled out across Lanarkshire, initial and update audits completed. Need to agree actions to address audit results.	30.4.09	MCN Executive Group
2.2	Ensure LPCAT roll-out is completed and use of the tool is embedded with all relevant health care professionals.	A Macmillan nurse was seconded to champion LPCAT roll-out and audit its use until 31.1.09. Funding has been identified to continue this role.	31.1.10	MCN Executive Group
2.3	Appoint new LCP team to raise awareness and conduct training in use of LCP across three acute hospitals, community settings and care homes in Lanarkshire.	New LCP team being recruited to ensure awareness/ training in place across all care settings. Team Leader in post, five nurses and admin. support by April '09.	30.4.09	Palliative Care Directorate
2.4	Audit use and quality of completion of LCP across all care settings. Develop action plan to address any issues raised	LCP team workplan under development.	ongoing to 31.3.12	Audit team/ MCN Exec. Group
2.5	Clinical Governance sub-group to review audit results for hospital and community pain tools and develop action plan to ensure pain is optimally managed	Pain tools developed and in use in hospital and community settings. Ongoing audit	30.6.09	MCN Clinical Governance Group
2.6	GP facilitator to liaise with all practices to encourage full attendance at monthly palliative care case meeting and comprehensive register. Arrangements to be audited.	87% of general practices signed up to GSF. Questionnaire being finalised to audit ongoing use. Variation in arrangements for multiprofessional meetings.	30.9.09	GP Facilitator/ Audit team
2.7	Assess the scope for linking the different NHS assessment tools and those used by partner organisations, mainly local authority colleagues.	Ongoing discussions with partner organisations continue to highlight the range of individual assessment tools recording similar dimensions despite attempts to link them e.g SSA.	31.12.09	MCN Executive Group
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There is a risk to full roll-out of the assessment tools (2.2, 2.5), participation in training (2.3) and case review meetings (2.7) in that full involvement of generalist staff is dependent on their line managers, some of whom have expressed concerns about the level of specialisation/additional training required of generalist staff. Need to explore usefulness of widening invitation to monthly case meetings to acute sector and social work. There is a need to have one folder where information can be added/taken away as required which would include the LPCAT, LCP, pain tools and anticipatory care planning tools that identify changing needs. Joint education sessions are necessary to ensure tools are understood and utilised properly to identify needs during the whole of the palliative care phase.				

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<p>ACTION 4: CHPs, palliative care networks, older peoples services and LTC teams in each NHS Board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centred and responsive to the needs of the diversity of the population at appropriate stages of the patient journey.</p>		<p><i>Action plan reference</i></p>		
<p>Identify through stating your objectives in relation to this Action Point, what you are trying to accomplish. Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.</p>		<p>Identify the changes (improvements) you have made / planning to make, in relation to each of your stated objectives.</p>	<p>Timescale</p>	<p>Responsible group or person</p>
<p>OBJECTIVES</p>		<p>CHANGES / IMPROVEMENTS</p>		
4.1	<p>The Palliative Care MCN will convene three exchange meetings per year per CHP locality between health and social services.</p>	<p>It has been agreed that the effectiveness of care planning is enhanced when staff know each other better. Hence a series of local exchange meetings is being established</p>	<p>30.9.09</p>	<p>MCN Manager/Co-ordinator</p>
4.2	<p>Link to 2.1 and 2.2 for those whose preferred place of care is a community setting</p>	<p>The LPCAT is designed to be left in the preferred place of care hence all those involved will have access to each others' notes/interventions creating in a single care plan</p>	<p>31.1.10</p>	<p>MCN Executive Group</p>
4.3	<p>Link to 2.6</p>	<p>Planned GSF re-audit will identify where facilitation is needed to encourage participation in regular case discussion meetings.</p>	<p>30.9.09</p>	<p>GP Facilitator/Audit team</p>
4.4	<p>The MCN will build on recent developments in carer support in North and South Lanarkshire to ensure palliative care remit is understood.</p>	<p>Resources have been allocated to carer support organisations in both local authorities</p>	<p>30.6.09</p>	<p>MCN Manager/Co-ordinator</p>
4.5	<p>The MCN will scope spiritual and cultural needs with the Equalities Officer and Head of Spiritual Care, including training needs of staff</p>	<p>Two of the recently appointed NHS chaplains have an interest in palliative care</p>	<p>30.9.09</p>	<p>MCN Manager/Co-ordinator</p>
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<p>In the process of joining up palliative care and associated documentation, it should be remembered that people always have the right to change their mind about the care planned. Communication is key to smooth transition between carers and care settings. This is aided by joint education sessions and should include care home staff. It should be borne in mind that the remits and responsibilities of different groups of staff do not always aid joint working, especially when different inclusion criteria apply e.g. sometimes people under 65 years are not eligible for certain places of care. Willingness to work together for the best interests of patients often enables a way forward to be found and the formation of better relationships across organisations is critical.</p>				

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ACTION 5: NHS Boards and CHPs should take steps to ensure that patients with any condition who have been assessed as having palliative or end of life care needs are included in primary care palliative care registers, are supported by a multi-disciplinary team, and have their care and that of their carers co-ordinated by a named health or social care professional.				Action plan reference
Identify through stating your objectives in relation to this Action Point, what you are trying to accomplish. Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point. Link to A34		Identify the changes (improvements) you have made / planning to make, in relation to each of your stated objectives.	Timescale	Responsible group or person
OBJECTIVES		CHANGES / IMPROVEMENTS		
5.1	The MCN will develop an action plan to ensure that all practices include non-malignant conditions on their palliative care registers, as detailed in the palliative care DES. Link to 1.1 re decision tool.	All practices have cancer registers. GSF audit tool has been drafted and will ask about non-malignant registers.	30.6.09	MCN Executive Group
5.2	Link to 2.2 and 2.6	LPCAT and palliative care multiprofessional meetings will ensure whole team support	30.1.10	MCN and GP Facilitator
5.3	Review existing arrangements to ensure appropriate care management approach adopted in line with different stages of disease trajectory and preferred place of care	Plan to convene a meeting of key stakeholders to scope this work and identify training needs of staff involved	30.9.09	MCN Manager/Co-ordinator
5.4	Encourage the remaining 14 practices to participate in the palliative care DES.	84 practices have signed up for the palliative care DES.	31.03.10	GP Facilitator
5.5	Ensure equitable provision of patient and carer support services across Lanarkshire, specifically targeting areas not currently covered.	Variety of provision at present, eg Maggie's Centre (Wishaw) Daziel Centre (Motherwell), The Haven (Blantyre), Little Haven (Forth), Kilbryde Day Hospice (East Kilbride).	31.03.11	MCN Steering Group
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.				
It would be helpful to clarify roles in relation to a named care manager, whether they are from health or social services. This person would explain what palliative care is to the family carers and co-ordinate seamless transitions between services and care settings. It can be very confusing for family carers to have a lot of people involved and there may need to be some gatekeeping of the number of visits in a day. A single point of contact for staff would also reduce the complication of many staff co-ordinating care plans. The needs being met may be wider than typically provided and may extend to complementary therapies in the home. The meeting of spiritual care needs is highly variable between individuals, but must not be forgotten.				

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ACTION 6: NHS Boards and CHPs should take steps, including the use of Patient Group Directions and Just in Case boxes where appropriate, to facilitate the use of anticipatory prescribing to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions.		<i>Action plan reference</i>		
OBJECTIVES		CHANGES / IMPROVEMENTS	Timescale	Responsible group or person
Identify through stating your <u>objectives</u> in relation to this Action Point, what you are trying to accomplish . Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.		Identify the changes (improvements) you have made / planning to make , in relation to each of your stated objectives.		
6.1	Develop an action plan based on results of PGD audit to cover all care settings.	Patient Group Directives in place for main palliative care drugs. Audit of use is ongoing. Initial results suggest there may be a need for focussed education	31.3.10	OOH Team Leader/MCN
6.2	Assess the need for 'Just in case' boxes and develop actions/ funding proposal to address findings. Assessment to include experience from other NHS Board areas	All the drugs that would be placed in 'Just in case' boxes are readily available, including for Out-of-hours service.	31.10.09	MCN to co-ordinate
6.3				
6.4				
6.5				
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.				
The response time in a crisis is crucial so anticipatory prescribing and 'Just in case' boxes are very valuable. The information about these needs to transfer timeously, particularly during changes to place of care. Not only does medication require to be where it is needed quickly, but the people in the place of care need to have the authority to administer it. Readmission to hospital is not necessarily a bad thing, but there needs to be a mechanism for alerting staff when this happens.				

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<p>ACTION 7: NHS Boards should work collaboratively with local authorities to produce service information directories for use by health and social care professionals and by patients and carers which outline how and when to access the services relevant to those with palliative and end of life care needs, including telemedicine and e-technology. These should be produced in a range of formats and communicated in different ways to ensure they are accessible and appropriate to the diverse needs of all groups.</p>				
<p>Identify through stating your <u>objectives</u> in relation to this Action Point, what you are trying to accomplish. Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.</p>				
OBJECTIVES		CHANGES / IMPROVEMENTS	Timescale	Responsible group or person
7.1	Determine what information would be useful to include in a Directory of Services. Link to 4.1	Initial meetings with representatives of North and South Lanarkshire Councils, further meetings being arranged.	31.10.09	MCN Manager/ Clinical Lead
7.2	Ensure that service information is available on the MCN web site and that there are clear links to and from this to other useful information	NHSL Long Term Conditions Board are establishing a Directory of Services which may in time obviate the need for a separate palliative care one.	30.6.09	MCN Manager/Co-ordinator
7.3	Ensure that there are adequate stocks of home packs to meet the need.	The Home Pack or 'gold folder' has service-related information for patients/carers/all staff involved, including named contacts on the LPCAT	30.6.09	MCN Manager/Co-ordinator
7.4	Convene a short life working group to make recommendations on the range of information formats required.	Information may be needed in Braille, large font, spoken word etc. Care should be taken not to use too much jargon, and a glossary should be supplied.	31.10.09	MCN Manager/Co-ordinator
7.5				
<p>Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.</p>				
<p>Ideas for what to include in information directories could extend to virtual tours of the various places of care e.g. hospitals, hospices, Beatson. Links to documentation such as Cancer backup materials. Much information will be available in the Home Packs which are left with the patients and therefore also available to care homes. It would be useful if they included a message asking for them to be returned when no longer required.</p>				

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ACTION 8: NHS Boards should implement consistent DNAR and associated documentation such as the example developed by NHS Lothian across all care settings and provide education to support the effective and appropriate application of the documentation and procedures. NHS Boards should enter into discussion with the Scottish Ambulance Service regarding adoption of DNAR policies which are consistent with the SAS End of Life Care Plan. <i>Action plan reference</i>				
OBJECTIVES		CHANGES / IMPROVEMENTS	Timescale	Responsible group or person
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8.1	The MCN will ensure that DNAR documentation is readily available to all relevant staff.	The Lothian DNAR documentation has been adopted for Lanarkshire.	30.4.09	MCN Manager/Co-ordinator
8.2	MCN to support the Resuscitation Officer to roll-out DNAR training across all care settings.	DNAR educational materials have been developed.	30.9.09	Resuscitation Officer/ MCN
8.3	The MCN will link with Scottish Ambulance Service and Acute Division colleagues to monitor the implementation of the DNAR policy and resolve any issues arising.	SAS representatives have been involved in the development of the DNAR policy, but issues are likely to arise during implementation that require collaborative resolution.	Ongoing to 31.3.10	MCN Executive Group
8.4				
8.5				
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.				
Collaboration is required across NHS systems to ensure effective implementation of the DNAR policy and full training of staff. The completed form could be left in a 'life pod' and a sticker placed in a prominent place in the home to identify its existence to emergency services, without causing undue distress with enquiries.				

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ACTION 9: NHS Boards and their partners should ensure equitable, consistent and sustainable access to 24 hour community nursing and home care services to support patients and carers at the end of life where the care plan indicates a wish to be cared for at home and this is compatible with diverse and changing patient and carer needs.		<i>Action plan reference</i>		
OBJECTIVES		CHANGES / IMPROVEMENTS		
Identify through stating your <u>objectives</u> in relation to this Action Point, what you are trying to accomplish . Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.		Identify the changes (improvements) you have made / planning to make , in relation to each of your stated objectives.		
		Timescale	Responsible group or person	
9.1	Associate Director of Nursing and Local Authority colleagues to explore options to fill the outstanding gap in provision.	Equitable access to Community Nursing and Home Care Services available 22/23 hours (gaps 8-9am, 5-6pm). NHSL has a contract with Marie Curie Nursing.	tbc	Assoc. Dir. Nursing/ Local Auths.
9.2	Link to 2.2	Roll-out of appropriate assessment/care planning documentation will support sharing of any changes in patient/carer needs.		
9.3	Support out-of-hours audit of palliative care issues	Out of hours service links well with palliative care services but it is timely to take stock of any relevant issues.	30.9.09	OOH Team Leader/ audit team
9.4				
9.5				
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.				
It may require additional resources to ensure comprehensive service availability. Transport can be an issue, particularly when the patient is too ill to travel by car/taxi and ambulance transport is not readily available.				

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ACTION 10: NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to die at home from any advanced progressive condition.		<i>Action plan reference</i>	
OBJECTIVES		CHANGES / IMPROVEMENTS	
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		Timescale	Responsible group or person
10.1	Link to 4.1	30.9.09	MCN Manager/Co-ordinator
10.2	Review current arrangements in relation to North and South Lanarkshire palliative care service needs	30.9.09	MCN Manager/Co-ordinator
10.3			
10.4			
10.5			
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.			
It would be helpful to agree response times for care packages to be put in place and equipment to be delivered and uplifted post bereavement. This can delay discharge if not readily accessed.			

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<p>ACTION 16: NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer, to all relevant professionals and across sectoral and organisational boundaries of patient information as identified in the ePCS regarding any patient identified as having palliative and end of life care needs and who gives consent.</p>		<p><i>Action plan reference</i></p>		
<p>Identify through stating your <u>objectives</u> in relation to this Action Point, what you are trying to accomplish. Your objectives should be written in such a way that they are SMART* and should reflect the priorities for your organisation to undertake this action point.</p>		<p>Identify the changes (improvements) you have made / planning to make, in relation to each of your stated objectives.</p>	<p>Timescale</p>	<p>Responsible group or person</p>
<p>OBJECTIVES</p>		<p>CHANGES / IMPROVEMENTS</p>		
16.1	<p>The MCN will finalise the paper-based palliative care summary document and ensure its availability for all relevant staff.</p>	<p>A draft paper-based version of the PCS has been developed which will hopefully be approved for use (including Out-of-hours) until ePCS is launched.</p>	<p>28.2.09</p>	<p>MCN to co-ordinate this</p>
16.2	<p>The MCN will seek ratification of the proposed consent arrangement.</p>	<p>Discussion suggested that consent is required only to share this information and that permission to access it could be sought from the patient/carer as required</p>	<p>tbc</p>	<p>MCN to co-ordinate this</p>
16.3				
16.4				
16.5				
<p>Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.</p>				
<p>Out of hours staff are critical to the provision of high quality palliative care services and they rely heavily on the timely transfer of the most recent information available.</p>				

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ACTION 20: To support implementation of this initiative NHS Boards will be asked to nominate a palliative and end of life care education champion to liaise with NES and to facilitate the sharing and spreading of good practice .		<i>Action plan reference</i>		
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OBJECTIVES		CHANGES / IMPROVEMENTS		
20.1	The MCN will nominate the Lead Clinician/GP Facilitator to become the Education Champion for Lanarkshire.	Educational meetings on different topics and for a variety of audiences are ongoing to ensure good practice is disseminated.	31.1.09	MCN Executive Group
20.2				
20.3				
20.4				
20.5				
Please describe below contextual information in relation to this Action Point including arrangements to monitor resources (value for money) and any associated key risks to implementation and how this will be managed.				
The Education Champion needs considerable time and back up to be effective in this role. Aspects that need some focus include encouraging generalists to prioritise and participate in palliative care training, defining appropriate staff who can put the learning into practice, and opening up the format of the training to include e-learning, videoconferencing and experiential learning workbooks. Many more people may need training to take on the role of care co-ordinator and given the vast number of staff involved in palliative care the education strategy is likely to be somewhat complex.				

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ADDITIONAL - AUDIT SCOTLAND RECOMMENDATION: NHS Boards should work with the voluntary sector to put into place commissioning and monitoring arrangements to ensure value for money is achieved

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OBJECTIVES		CHANGES / IMPROVEMENTS		
AS1	Chair of Marie Curie contract meeting to forward activity audit reports to Clinical Governance sub-group	Marie Curie Contract meeting receives regular audit reports on activity. These will be shared with Clinical Governance sub-group	ongoing	Chair of Marie Curie contract mtg.
AS2	General Manager of the Palliative Care Directorate to review existing contract monitoring arrangements to identify any actions needed or additional requirements.	All voluntary organisation contracts are regularly monitored via the submission of audit data to the Palliative Care Services Directorate.	30.9.09	General Manager, Pall. Care
AS3				
AS4				
AS5				

Please describe below contextual information in relation to this Action Point including any associated key risks to implementation and how this will be managed.

Other contracts to be monitored: St Andrew's Hospice, Strathcarron Hospice, CAB/Macmillan service, Kilbryde Hospice. There is a question about how non-contracted voluntary organisations fit in. It will be challenging to demonstrate value for money. Accountability processes will need to be made explicit. NHS Lanarkshire will also need to have processes in place to monitor progress with this Delivery Plan. There is support for greater provision of drop-in facilities offering a range of therapies, advice and support.

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