

Argyll and Bute Delivering Choice Programme

April 2013 – February 2016

Executive summary

Jenny Dryden, Project Officer, Marie Curie

Diana Hekerem, Divisional Business & Service Development Manager, Marie Curie

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Background

Argyll and Bute

- Much of the population of Argyll and Bute is spread out across the vast remote and rural environment; 75% of the population live in remote small towns or rural areas¹
- The number of people in Argyll and Bute aged over 75 is projected to increase by 75% by 2037².
- Demographic changes are likely to have significant implications for future health and social care delivery over the next 20 years and have been a key driver of change in Scotland.
- Palliative care services are one area where demand is likely to increase, as an increasing percentage of the population age and experience illness.

Delivering Choice Programme

- Marie Curie (Delivering Choice Programme) was commissioned in 2012 to review and redesign palliative and end of life care in Argyll and Bute through Reshaping Care for Older People, a 10 year Scottish Government programme that aims to improve services for older people by focusing on prevention and anticipatory care.
- The Delivering Choice Programme (DCP) uses an evidence based approach to improve palliative and end of life care in various areas of the UK; assessing gaps in local service provision and utilising expertise in programme management and service redesign to develop and implement new initiatives to address these gaps.
- **Phase 1** reviewed the population of Argyll and Bute and their health needs; general palliative and end of life services for patients and carers, including Third Sector services; specialist palliative care services; and transportation.
- **Phase 2** saw workshops held with local stakeholder including NHS, Social Work, Independent Sector and Third Sector to generate potential initiatives and solutions for the problems facing Argyll and Bute. Six projects were approved for implementation.
- **Phase 3** saw six projects approved, implemented and evaluated.

1 The Scottish Government (2010). Scottish Government Urban Rural Classification, Retrieved from <http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/UrbanRuralClassification>

2 National Records of Scotland. (2015a). *Argyll & Bute Council Area - Demographic Factsheet*. Retrieved from <http://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/argyll-and-bute-factsheet.pdf>

Project outlines and successes

1: Marie Curie Nursing Service (Managed Care)

Gaps and challenges identified

- Phases 1 and 2 of the DCP identified gaps in terms of home care and out of hours support for palliative and end of life care patients.
- These included a need for more flexible visits for patients, including shorter visits during the day to provide respite care for carers, and increased partnership working with existing community providers to deliver high quality home support, particularly during out of hours.

Solutions/improvements

- A new Marie Curie Nursing Service model, known as Managed Care, was implemented. Managed Care allows for local coordination through a Marie Curie Senior Nurse, supported by a team of Marie Curie registered nurses and healthcare assistants.

Key achievements

- Managed Care has seen a number of benefits during the first 18 months of the service.
- The service saw patients before they reach urgent status or a crisis point, with 25% of referrals classified as urgent during the first year and 16% classified as urgent during the second year of the service so far. Before the Managed Care service began, 45% of referrals were classified as urgent
- During the first year of the service, the equity for all patients with a terminal illness improved; 31% of patients who received the service had a non-malignant diagnosis, compared to 23% before the service began.
- The total number of daytime visits also increased, from 41 in 2013/2014 to 73 during the first year of the service. In year 1, daytime visits made up 10.5% of the total visits, compared to 6% in 2013/2014.
- District Nurse and patient family feedback about the service was positive, with families praising the Marie Curie Nurses for their care, compassion, commitment and reliability

2: Guidance and Support for Informal Carers

Gaps and challenges identified

- During phases 1 and 2 of the DCP it was highlighted that there were no specific programmes delivering information and guidance on palliative and end of life care issues for carers who are caring for friends or family members with a serious illness.

Solutions/improvements

- A comprehensive package of training sessions was developed to address the various issues faced by 'informal carers', who may already be looking after a friend or family member with palliative care needs, or may have to in the future as their loved one's illness progresses.
- These were piloted in the Oban, Lorn and the Isles locality, in partnership with North Argyll Carers Centre, NHS Highland and Alzheimer Scotland.

Key achievements

- A focus group carried out at the end of the sessions indicated that overall the carers found the sessions helpful and informative, giving them the chance to share tips and experiences.
- The group also allowed them to get to know relevant healthcare professionals, ask for help and be signposted towards other resources

3: Palliative Care in Care Homes

Gaps and challenges identified

- Palliative care provision in care homes was discussed during phases 1 and 2 of the DCP and it was highlighted that care homes could be further supported in the delivery of palliative and end of life care.

Solutions/improvements

- This project aimed to provide this support by delivering palliative care training to care home staff, identifying palliative care champions and providing guidance on out of hours support and standard palliative care processes and documents.

Key achievements

- Partnering with local Macmillan Clinical Nurse Specialists, the training programme was piloted in Cowal and trained 84 members of staff.
- The palliative and end of life care training had clear benefits for staff members' knowledge and confidence in various palliative and end of life care issues including communication skills; assessment and care planning; and symptom management, maintaining comfort and wellbeing.
- In total, 97% agreed that they were likely to use what they learned in the training in their day-to-day work and 95% agreed that they found the training sessions useful.

4: Best Practice Transport Guidance for Palliative Patients

Gaps and challenges identified

- The transport difficulties faced by those living in Argyll and Bute were discussed extensively during phases 1 and 2 of the DCP.

Solutions/improvements

- Following discussions between NHS Highland and NHS Greater Glasgow and Clyde, and between the various transport providers in Argyll and Bute, a patient and carer information booklet was developed.

Key achievements

- The booklet provides guidance on options for all patients, including those with palliative and end of life care needs, who require transportation for medical appointments and social needs.
- The booklet contains information on community transport providers, Scottish Ambulance Service Patient Transport Services and sources of potential travel funding such as the Highlands and Island Patient Travel Scheme.
- This booklet will be distributed widely throughout Argyll and Bute.

5: Remote and Rural Helper service

Gaps and challenges identified

- People living in remote and rural communities such as Argyll and Bute often do not have the same access to care and support services at the end of life as those living in urban areas; they are more likely to be physically and geographically isolated than those living in urban settings.
- During phases 1 and 2 of the DCP a need was identified for a volunteer service to provide emotional and practical support for palliative care patients and their families within the home environment, tackling the social isolation that can affect people living with a terminal illness in a rural community.

Solutions/improvements

- Marie Curie Helper service was identified as a solution that provides companionship, emotional and practical support to those living with terminal illness, and their families.
- Recognising the rural challenges, 'Remote and Rural Helper' was developed as the best way of providing this support in Argyll and Bute by partnering with existing voluntary organisations to make use of existing volunteer resources and relationships.
- Remote and Rural Helper will see Marie Curie partnering with Cowal Elderly Befrienders, North Argyll Carers Centre and Shopper Adie to provide governance, training, and guidance to up-skill and support current volunteers in terms of palliative care knowledge.
- Volunteers would therefore be trained in each locality and ready to be matched to clients who require support through their journey with terminal illness.

Key achievements

- Funding was identified through the Big Lottery Fund programme: Investing in Communities (Supporting 21st Century Life) and the project has been successful in progressing to the second stage of the funding application. If successful, a three year project will be implemented to pilot the Remote and Rural Helper service in Argyll and Bute.

6: Health Promoting Palliative Care

Gaps and challenges identified

- A lack of openness regarding talking about death and dying can negatively affect individuals, carers and families. For example, those awaiting arrangement of a Power of Attorney when their loved one has lost capacity often experience emotional and financial strain.

Solutions/improvements

- Health Promoting Palliative Care encourages individuals and communities to have open conversations about death and dying.

Key achievements

- To mark *Dying Matters Awareness* week, three events were held in Argyll and Bute to encourage the general public to have conversations around death, dying and bereavement. A photo exhibition was also on display in a number of locations around Argyll and Bute to help people positively remember their Absent Friends during the *To Absent Friends* festival.
- The project also supported the set-up of a Power of Attorney campaign for delivery across Argyll and Bute. Joining the 'Start the Conversation' Campaign resulted in the creation of Argyll and Bute specific material such as information leaflets, a web page and TV adverts. Briefing notes on Power of Attorney were also distributed to various organisations including Argyll and Bute pharmacists, GPs, solicitors and libraries.

Recommendations

The Delivering Choice programme makes a number of recommendations about the future of palliative care in Argyll and Bute.

1. It is recommended that the Managed Care model of the Marie Curie Nursing Service continues in Argyll and Bute, due to the benefits seen during the first two years of the service.
2. It is also recommended that the guidance and support sessions for informal carers, who are caring for friends or family members with palliative care needs, continue and are rolled out across Argyll and Bute.
3. It is recommended that palliative care training continues to be delivered to care home staff and that this is standardised across Argyll and Bute.
4. It is recommended that the transport booklet is disseminated by the Palliative Care Development Steering Group and reviewed by the group after two years.
5. If successful in receiving funding, it is recommended that the Remote and Rural Helper service is implemented and evaluated in Argyll and Bute.
6. It is recommended that awareness of issues surrounding death, dying and bereavement (such as Power of Attorney) continue to be promoted throughout Argyll and Bute and that the Palliative Care Development Steering Group look to encourage participation in annual events such as Dying Matters Awareness week.

Conclusions

- The benefits of partnership working were evident throughout the Delivering Choice Programme. The groups that guided the individual projects had representation from a range of stakeholders including NHS Highland, Argyll and Bute Health and Social Care Partnership, NHS24, Scottish Ambulance Service, North Argyll Carers Centre, Alzheimer Scotland and Care Home Managers, among others. This enabled the programme to build relationships with local partners, ensuring that projects met the needs and had the support of the local area.
- Sustainability of each of the projects has also been ensured through this partnership working, with the Palliative Care Development Steering Group taking responsibility for reviewing the programme recommendations and their implementation going forward.
- Implementing these recommendations will allow for the continued success of projects such as the Marie Curie Nursing Service which, in addition to the benefits listed previously, is projected to care for around 35 more patients during its second year than before the new service began.
- In addition, Macmillan Clinical Nurse Specialists will continue to provide palliative care services such as training for care home staff and will liaise with local carer centres regarding further support for carers who are caring for friends or family members with terminal illness; ensuring that the benefits of these projects are spread throughout Argyll and Bute.
- In order to monitor palliative care services in the longer term, it is recommended that the Argyll and Bute Health and Social Care Partnership invest resources in determining the most appropriate outcome measures for palliative and end of life care in Argyll and Bute and implementing these into routine care. These should include measures that capture people's accounts of their experience.
- Finally, it is also recommended that the Argyll and Bute Health and Social Care Partnership use the findings from the Delivering Choice Programme as evidence to help develop the content of their Strategic Commissioning plan in relation to palliative and end of life care services.

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For more information contact:

Diana Hekerem
Marie Curie
133 Balornock Road
Glasgow G21 3US
Phone: 0141 557 7552
Email: diana.hekerem@mariecurie.org.uk
Follow us on Twitter @mariecurieuk

Visit www.mariecurie.org.uk/argyllandbute

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Care and support
through terminal illness