

Conclusion

The Advanced Dementia Practice Model provides an integrated and comprehensive approach in responding to the most complex phase of dementia.

The Model promotes the wellbeing and quality of life of both the person with advanced dementia and those closest to them. It also provides the essential support to care homes and those providing day-to-day care.

The Advanced Dementia Practice Model delivers the final essential component in supporting people living with dementia from diagnosis to end of life.

Recommendations

The Scottish Government accept and recognise that on the basis of this report, there is clear evidence that once a person has reached the advanced stage of dementia, all their needs are health care needs.

Each Health and Social Care Partnership in Scotland provides a Dementia Practice Coordinator for every person with dementia as they progress to the point of requiring community and health care services.

The Dementia Practice Coordinator is confirmed as an additional Enhanced role delivered within the existing and established professional groups such as social workers, nurses and allied health professionals, with the appropriate authority to commission and coordinate the required level of care and support.

The Promoting Excellence Framework is used to ensure the Dementia Practice Coordinator meets the Enhanced practice level and that all staff within the 8 Pillars Team are operating at a minimum of Skilled level.

The Advanced Dementia Practice Model is tested as part of the objectives of the National Dementia Strategy 2016 and if successful, an Advanced Dementia Specialist Team is established in each Health and Social Care Partnership in Scotland by 2020.

For further information or a copy of the full report contact Alzheimer Scotland:

By email: publicpolicy@alzscot.org

By telephone: 0131 243 1453

With grateful acknowledgements to:

Alzheimer Scotland staff throughout Scotland who facilitated the consultation

People living with dementia, practitioners and representative organisations who took part in the consultation

This work was funded by the RS Macdonald Charitable Trust



Advanced Dementia Practice Model:

understanding and transforming advanced dementia and end of life care



Summary of the model and recommendations for putting it into practice

Introduction

Increasing life expectancy means more of us will experience dementia and the proportion of people dying with dementia will grow. Advanced dementia presents the most complex phase of the illness and calls for a coordinated and planned approach to care.

The Advanced Dementia Practice Model sets out an integrated and comprehensive approach to support. It combines the skill and understanding of the existing 8 Pillars Team¹ and Dementia Practice Coordinator and introduces the Advanced Dementia Specialist Team to provide optimum care.

Building on developments in post diagnostic support and community support, the Model will enhance the quality of life, resilience and comfort of people living with advanced dementia.

From the point of diagnosis to the end of life, every person with dementia and their family deserves nothing but the best care we have at our disposal. To achieve this we must change our current practice and transform our system. The Advanced Dementia Practice Model provides the key to the best possible care in advanced dementia and at end of life. We look forward to working alongside our many partners to test and refine the Model.

Advanced Dementia Specialist Team

The Dementia Practice Coordinator will facilitate the input of the Advanced Dementia Specialist Team to enhance the care that will continue to be provided by the 8 Pillars Team. The Advanced Dementia Specialist Team will provide specialist input where this does not already form part of the 8 Pillars Team.

The entry point to the Advanced Dementia Practice Model is determined by the level and complexity of need requiring substantive health care as assessed by the Advanced Dementia Specialist Team. The range of factors necessitating this approach will be specific to each individual but likely to be determined by the progressed physical experience of dementia and interplay of co-morbid illness.

Practitioners will be located within the Advanced Dementia Specialist Team on full, part time or consultancy basis as required. There will be an emphasis on shared learning across this group of practitioners, with a focus on training to Expertise Level of the Promoting Excellence Framework². Care pathways, team lead and structure will be determined by what is appropriate within the local context.



¹ 8 Pillars Team includes all those providing care and support: care homes, care at home, family carers, general practitioner and specialist practitioners involved in the person's care before transition to the Advanced Dementia Practice Model
² Scottish Government (2011) Promoting Excellence: a framework for all health and social care staff working with people with dementia, their families and carers Edinburgh

Advanced dementia practice model:

understanding and transforming advanced dementia and end of life care

Dementia Practice Coordinator

The Dementia Practice Coordinator will provide the planning and coordination for the Advanced Dementia Practice Model. They will combine the expertise and understanding of the 8 Pillars Team and Advanced Dementia Specialist Team. They will provide a structured approach to integrate specific supports to respond to the symptoms of advanced dementia, enhance coping and prevent crisis. They will coordinate delivery of the care plan, monitor its effectiveness and ensure its timely review. Working with the 8 Pillars Team, they will identify critical points when the person and their carer require alternative or additional interventions and facilitate the contribution of the Advanced Dementia Specialist Team.

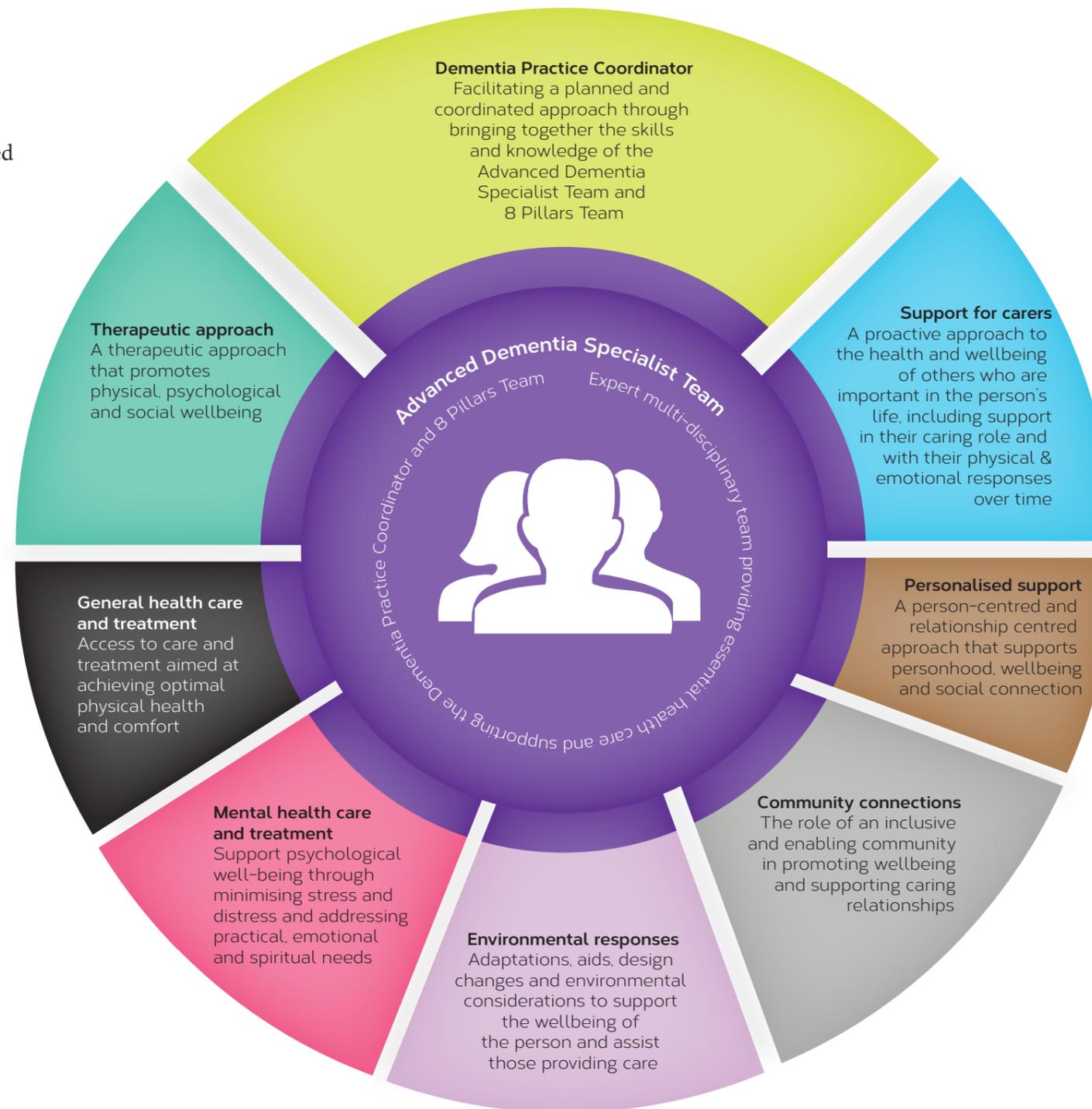
Dementia Practice Coordinators are named and skilled practitioners operating at the Enhanced Level of the Promoting Excellence Framework. The role relies upon their authority and status to commission and control interventions and harness the contribution of a wide range of practitioners.

General health care and treatment

The Advanced Dementia Specialist Team will provide advice, assessment and treatment in responding to complex symptoms of advanced dementia, underlying health conditions and complications that arise such as infection. They will support complex clinical considerations and specialist assessment in consultation with the Dementia Practice Coordinator and 8 Pillars Team.

Mental health care and treatment

The psychological wellbeing of the person will be supported through the contribution of the Advanced Dementia Specialist Team to enhance the care provided by the 8 Pillars Team. This will support the use of person-centred approaches in responding to the unique biological, psychological and social factors that may be causing stress and distress in the person with dementia.



Personalised support

The Advanced Dementia Specialist Team will bring knowledge and expertise in equipping the 8 Pillars Team with person-centred approaches to communication, care-giving and social connection. The Advanced Dementia Specialist Team will support care staff and family carers in delivering care around complex physical, emotional and psychological needs. It will support approaches that maintain and enhance existing caring relationships and promote dignity and personhood.

Therapeutic approach

The Advanced Dementia Specialist Team will support the 8 Pillars Team in providing therapeutic approaches and interventions that facilitate communication and provide meaningful occupation. It will equip family carers and care workers with approaches that foster connection and shared experience with the person with dementia.

Support for carers

The Advanced Dementia Practice Model recognises the carer as an individual in their own right and responds to their personal need for emotional and practical support. The Advanced Dementia Specialist Team will build on the support provided by the 8 Pillars Team in maintaining the health and wellbeing of the family carer.

Environmental responses

Environmental considerations are a key component of supporting people living with advanced dementia. They can address some of the challenges caused by the symptoms of advanced illness and co-existing conditions. The Advanced Specialist Dementia Team will deliver specialist advice and assessment in supporting the 8 Pillars Team to promote physical, social and psychological wellbeing through environmental adaptations and the provision of appropriate equipment.

Community connections

Community connections can help reduce the sense of isolation and support the caring relationship through providing practical support. The Dementia Practice Coordinator and 8 Pillars Team will work to develop these supports and identify where additional support is required from the Advanced Dementia Specialist Team in supporting community connections for both the person with dementia and their carer.