



## End of Life care for people with dementia

### What is the GSF End of Life Care for people with Dementia Care Programme ?

The GSF programme in End of Life Care for People with Dementia aims to improve the way people with dementia are cared for in the last years of life following diagnosis. A key focus of the programme will be to enable people living with dementia to live well and die well in their usual place of residence, improving knowledge and awareness of staff of changes and thereby reducing crises and avoidable hospitalisation.

### What is the impact? - how this will make a difference in care.

The programme has 4 modules:

#### 1. Awareness

- Awareness of the impact of dementia on people
- Seeing the person with dementia - person centred care
- Maintaining dignity and respect

#### 2. Pain & Distress

- Recognising decline
- Recognising masked pain and distress
- Understanding other symptom management

#### 3. Communication & wishes

- Communicating and better listening
- Advance Care Planning discussions - wishes and preferences
- Supporting carers

#### 4. Reduce hospitalisation at end of life

- Improving cross boundary communication - reduce crises
- Reducing avoidable hospitalisation - Keep safe at home
- Care of the dying

### Why is Dementia so important ? ... and how should we respond?

“[We] call for greater innovation to improve the quality of life for people with dementia and their carers while reducing the emotional and financial burden....and to call upon all sectors to treat people affected by dementia with dignity and respect, and to enhance their contribution to dementia prevention, care and treatment where they can.”

*G8 Dementia Summit declaration, December 2013*

“Two and a half cheers for ... the G8 leaders for their magnificent initiative. I hope, fervently, for a cure (for dementia ). However, let no one be in any doubt that the critical issue here is the investment in care and it is on this issue that we should hold governments to account”.

*Professor Martin Prince, Global Observatory for Ageing and Dementia Care, Kings College, London*



# Gold Standards Framework Centre C.I.C. enabling a 'Gold Standard' of care for all people nearing the end of life

The National GSF Centre in End of Life Care is the UK's leading provider of training for generalist frontline staff .

## Who will find this useful?

- Care home staff - nursing and residential
- Domiciliary care workers
- Anyone involved in care for people with dementia
- Volunteers, clergy and others
- District Nurses, practice nurses and others in primary care teams
- Hospital staff - Acute and Community

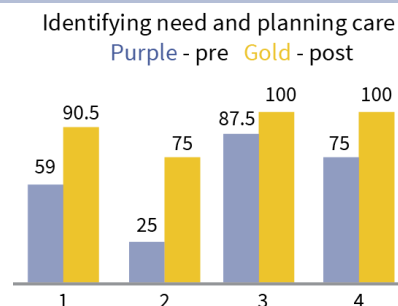
## How do you access the training?

Giving you easy distance learning access at home or work.

The training programme, first piloted in 2013 supported by the DH Dementia Strategy Implementation group, is an easily accessible distance learning, quality improvement training programme on the GSF Virtual Learning Zone. It includes 4 modules taken over 3-4 months, with specific outcomes and goals, individual and organisational evaluations to evidence measurable and demonstrable change in the care of people with dementia at the end of life.

## Pilot Phase 1—Results. Overall improvements gained

1. Advance Care Planning, increase of 36% (59% to 95%).
2. Increased identification of people with dementia in the last year of life—increase of 50%. (25% to 75%).
3. Developing of a care plan for final days – increase of 12.5%. (87.5% to 100%)
4. Increased discussions with other professionals – increase of 25%. (75% to 100%).



“I understand a lot better why people do certain things, and how simple things make a big difference. Thank you”.

*Care Assistant - Phase 3*

“ I have more confidence in obtaining treatment and support for my person with dementia, when needed”.

*RGN in care home - Phase 1*

“We feel we have gained in confidence to have discussions with relatives and feeding back to the multi-disciplinary team.”

*Nursing Home Manager - Phase 1*

“The Gold Standards Framework Dementia Care Training Programme is an important element of this work and will help ensure that people with dementia are given the best possible care at the end of life.”

*Alistair Burns, National Clinical Lead for Dementia, Department of Health.*

For further information and costs, please contact  
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