



Understanding stress and distress in dementia:

the importance of a person-centred
preventative approach



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Section 1: Introduction

Stress in dementia has a wide range of underlying causes that reflect the unique experience of the person within the context of their environment and personal background. Stress can be present at any time throughout dementia and is not necessarily solely or directly related to the illness. People with dementia will become less able to advocate for themselves and communicate their experiences to alleviate stress, making the responses of others of increasing importance as the illness advances.

A biopsychosocial^a and preventative approach is required in response to stress and to minimise the occurrence of distress. The needs and stress experienced by those providing care is also a crucial consideration.

This report provides an understanding of the nature of stress and distress in dementia. It then outlines responses based on evidence and good practice. This report is a companion to the Alzheimer Scotland reports outlined in the following section and provides further knowledge in relation to this key issue in dementia. The aim of this report is to provide knowledge and understanding to a wide audience, including professionals, carers and families, to add value in sharing current good practice and resources.

Scotland has a well-developed policy and practice framework in relation to stress and distress. NHS Education for Scotland has developed key resources and training in supporting key practitioners, professional carers and families. However, there can be a gap in practice – it is important that people with dementia, professional carers and families benefit from the optimum knowledge and support available to maintain quality of life.

^a Biopsychosocial recognises the physical, social and psychological impact of dementia. This means understanding and responding to the needs of the person in a holistic way.

1.2 Background to report

Alzheimer Scotland carried out a large-scale consultation with key stakeholders^b to inform the development of the Advanced Dementia Practice Model (2015). The findings from this consultation have informed this report. Further discussions for this report have also been held with key practitioner groups providing care and therapeutic responses to people with dementia, family carers and support to those providing day-to-day care. This included psychology, psychiatry, nursing and allied health professionals.

This report sits within Alzheimer Scotland's vision of how Scotland can lead the way in dementia care (Figure 1). The core principles presented in this report are a key element of each phase of the illness. They reflect the importance of the psychological wellbeing of the person and providing a therapeutic approach in responding to individual needs and honouring personhood.

The Alzheimer Scotland (2011) Five Pillar Model provides an evidence-based approach to supporting people during the post-diagnostic time. The Eight Pillar Model (2012) and Advanced Dementia Practice Model (2015) then provide an approach to the continuity of care as the illness progresses to support people to remain where they are supported by people they are familiar with.

These Models provide the mechanism to ensure key specialists are brought in to support existing care to respond to the increasing complexity and intensity of needs as dementia advances. This has a key role in providing a preventative approach in stress and distress. Transforming Specialist Dementia Hospital Care (2018) sets out the appropriate approach, including stress and distress, where there is a need for care to be provided in a specialist dementia unit.

Connecting People, Connecting Support (2017) outlines the allied health professional (AHP) approach to supporting people living with dementia. This includes the role of AHPs in maximising physical health and psychological interventions and therapies. For some AHPs^c working with people living with dementia will be an important focus of their role and they will support carers and deliver specialist interventions.

This report is intended as an addition and accompaniment to the reports outlined above. It aims to provide an understanding of the phases of the illness, different care environments and practitioners required in responding to the occurrence of stress and distress.

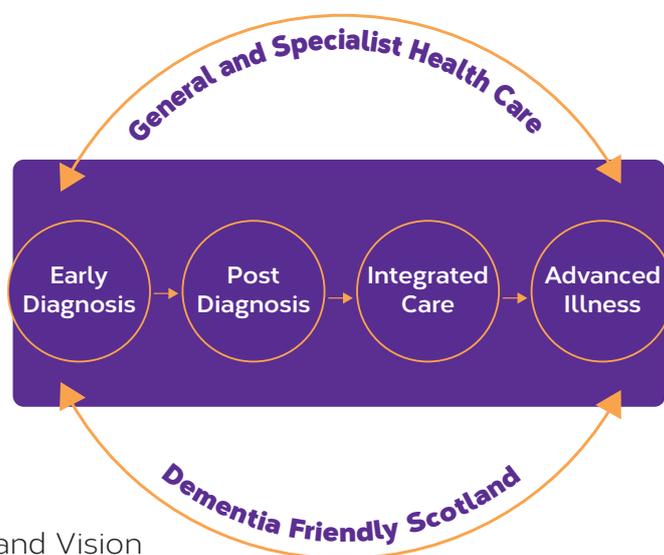


Figure 1: Alzheimer Scotland Vision

^b This involved an open consultation from November 2014 to June 2015 – 50 responses received to consultation paper and over 30 discussion group sessions and individual meetings held. Participants included people with dementia, families and friends and individual practitioners and practitioner groups.

^c Such as occupational therapists, physiotherapists, dieticians and speech and language therapists

1.3 Policy and practice context

The National Dementia Strategy for Scotland^d is underpinned by the “Charter of rights for people with dementia and their carers in Scotland” (2009). This includes ensuring that the human rights of people with dementia are respected, protected and fulfilled. The Charter also stipulates that people with dementia have the right to health and social care services provided by people with an appropriate level of training on dementia and human rights.

Understanding the nature of stress and distress in dementia is important to everyone providing care and support to people with dementia. Responsibility is with everyone and requires a collaborative approach. The way in which stress and distress is viewed will determine the responses implemented in supporting the wellbeing and human rights of the person. The approach of those delivering care^e is a key component in responding to stress and minimising the occurrence of distress (James and Jackman 2017). Their knowledge and understanding of the person, recognition of needs and responses to moment-to-moment experiences are pivotal and will have the greatest impact in reducing the occurrence of stress and distress. At times specialist practitioners will be required to support the understanding of individual needs and the delivery of person-centred responses.

There are a range of health and social care practitioners important to supporting a preventative approach alongside family carers, care homes, care at home and day care services. This includes allied health professionals, psychologists, psychiatrists, mental health and general nurses, primary care staff, pharmacists and social workers. This should be multi-disciplinary, planned and coordinated within the context of the community and in specialist dementia hospital care.

The Promoting Excellence Framework (2011) takes this forward into practice through outlining the knowledge and skills required by health and social care practitioners. This is set out in four levels of skill and knowledge determined by the practitioner’s role and level of responsibility. The importance placed on responding to stress and distress is evident throughout the levels in preventing, identifying and responding to the symptoms and underlying causes in supporting wellbeing and quality of life.

Hospital care is a key care setting in responding to stress and distress in dementia. The 10 Dementia Care Actions in Hospital, developed by an expert Dementia Standards in Hospital Implementation and Monitoring Group, are aimed at acute hospital care. Care Action 9 is specifically targeted at this key issue “Minimise and responds appropriately to stress and distress”.

^d The first National Dementia Strategy was published in 2010, with subsequent updates published in 2013 and 2017

^e This includes family carers, care homes, care at home service and day care

10

Dementia Care Actions in Hospital



1

Identify a leadership structure within NHS boards to drive and monitor improvements.

2

Develop the workforce in line with Promoting Excellence

3

Plan and prepare for admission and discharge

4

Develop and embed person-centred assessment and care planning.

5

Promote a rights-based and anti-discriminatory culture.

6

Develop a safe and therapeutic environment.

7

Use evidence-based screening and assessment tools for diagnosis.

8

Work as equal partners with families, friends and carers.

9

Minimise and respond appropriately to stress and distress.

10

Evidence the impact of changes against patient experience and outcomes.

1.4 Outline of report

Section 2: The nature and experience of distress in dementia

This section provides an understanding of stress in dementia, the factors that contribute to the creation of distress and the ways in which they can be expressed.

Section 3: Core principles and approaches to appropriate care

This section sets out the core principles and evidence-based approaches in responding to stress and distress.

Section 4: Conclusion

The final section presents recommendations to ensure the key principles and good practice approaches are in place to support the health and wellbeing of people with dementia and their carers.

Section 2:

The nature of stress and distress in dementia

2.1 Introduction

This section provides a description of the factors that contribute to the creation of stress and distress in dementia and the ways in which it can be expressed. These factors reflect the biological, physical, psychological, emotional and social elements that are unique to each person with dementia within the context of their environment.

It is likely that the person with dementia will experience stress at times throughout the course of the illness. This includes the time of the emergence of the symptoms of illness, impact of diagnosis, the adaptation process following a diagnosis and as the illness progresses. Not all stress will be solely or a direct result of the disease process.

The responses of others are of key importance in alleviating stress and preventing distress. This should also encompass an understanding of the interaction of the person with dementia within the social and physical environment.

2.2 What is stress and distress in dementia

Stress is a naturally occurring human emotion. People with dementia, their families and those providing care all likely to experience stress at times. A person may be able to function normally with a relatively low level of stress, but as stress increases they are likely to become anxious. If their 'stress threshold' is reached things will become overwhelming and they may no longer be able to function effectively (Brown 2018).

Dementia will result in the person having a "progressively lowered stress threshold" (Hall and Buckwalter 1987). This means that the level of stress the person can tolerate decreases incrementally over time so that the 'stress threshold' is reached more quickly with lower levels of stress. It is important to support people with dementia and their families to have a sense of control over their situation and develop coping strategies in response to distress.

Stress is not distress and there is a process of moving from one to the other. Distress can be considered as an outcome of unresolved stress (Brown 2018). The diagram below (Figure 2) illustrates some of the factors in dementia that may put people at greater risk of stress progressing to distress. There will be opportunity to intervene and a preventative approach will be important in halting the progression from stress to distress.

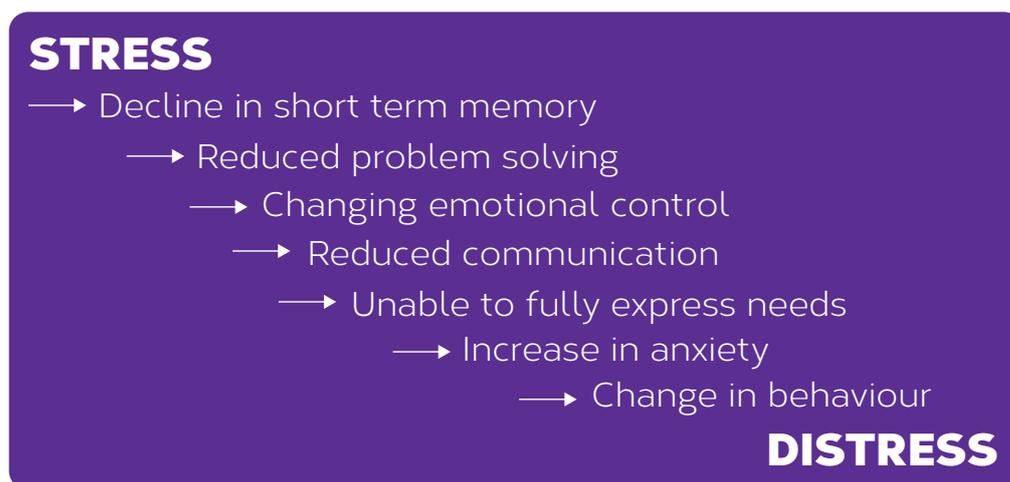


Figure 2: Stress to distress

Source: Brown (2018) 2.3 Diagnosis and living with dementia

2.3 Diagnosis and living with dementia

The period of noticing symptoms preceding the diagnosis of dementia will be stressful. The changes and losses connected to the emergence of the symptoms of illness will have created a challenge to the person's sense of self and future expectations (Kinnaird 2013). People with dementia can experience high levels of stress with the fear and uncertainty of living with the illness, within their close relationships and in anticipating their future (Sharp 2017).

Recognition of and responding to the subjective experience of dementia can help to reduce the level of stress experienced by the person. Supporting the person to have a greater sense of control over their own lives and to develop coping strategies were amongst the features in working towards reducing personal stress (Sharp 2017). This will be important in supporting the person with dementia and those closest to them in maintaining wellbeing and having the best quality of life possible.

2.4 Stress and distress as the illness progresses

As the illness progresses there are many factors associated with the illness that can increase the likelihood of stress and put the person at risk of distress. James and Jackman (2017) provide an iceberg analogy (Figure 3) to illustrate the underlying and interrelated factors that contribute to the expression of stress and distress in the moment. The individual factors encompassed within the triangle interact and are influenced by the external factors within the social and environmental context.

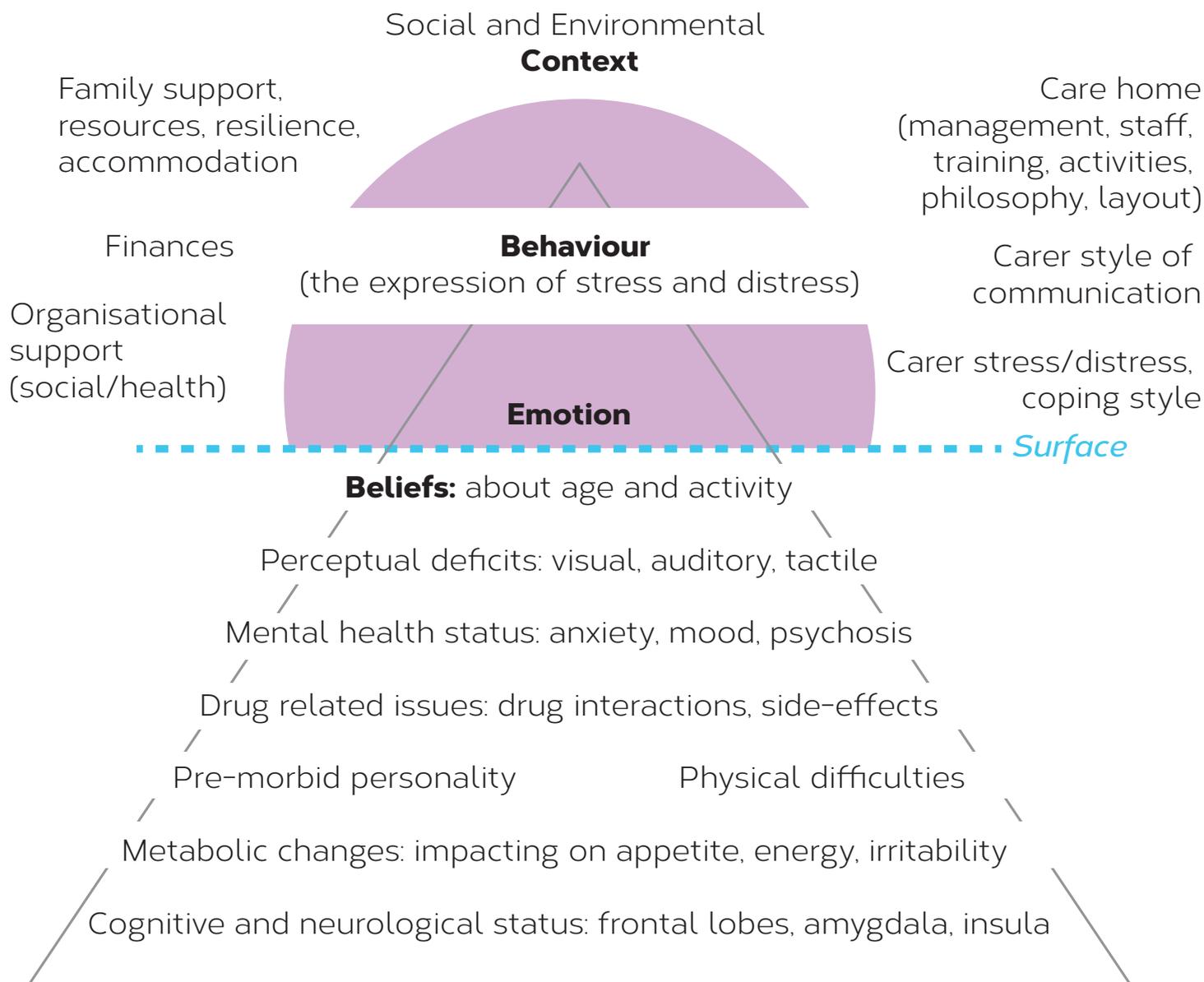


Figure 3: Iceberg analogy
(Source: James and Jackman 2017)

2.4.1 Cognitive processes and psychological function

Dementia has a progressive and profound impact on cognitive process and psychological functions. The effect will vary between individuals and be influenced by the type of dementia and phase of illness. Whilst memory impairment is most frequently acknowledged, many other factors are affected including attention, language, perception, motor skills and executive functions (NES 2012). It also impacts adversely on the ability to carry out activities of daily living due to cognitive losses which in turn can have a negative impact on the person's psychological wellbeing.

This will begin to impact upon the person's ability to do such things as interpret information, make sense of their environment and identify the location of physical pain. It will also mean that people become less able to advocate for themselves and express their needs in a way that is understood by others.

The damage to cognitive processes will mean that the person with dementia may have a different perception of the current context to other people (James and Jackman 2017). Level of insight and understanding of present circumstances will be a key influencing factor in the creation of stress and distress in dementia. Where the person believes they continue to have the responsibilities of an earlier time in their life, such as collecting children from school or going to work, they may become anxious if they perceive those around them to be stopping them in this pursuit.

2.4.2 Psychological symptoms in dementia and comorbid mental health conditions

It is common for people with dementia to experience a prolonged period of adverse emotions that can be classified as a mental illness (NES 2012). Depression may occur frequently in dementia and can be expressed in withdrawal and apathy. It may also result in agitated behaviour such as pacing. In later life depression frequently does not present as described in the textbook, even in the absence of dementia. Anxiety is also common in people with dementia and can be expressed through restlessness and being in a constant state of vigilance.

A person with dementia may also experience stress and distress because of an enduring mental health condition such as severe anxiety, depression, schizophrenia or other psychotic disorder. Psychotic symptoms include hallucinations and delusions. This may result in hearing or seeing things that do not exist (hallucinations) or unusual beliefs that are not based on reality (delusions). These can appear within the context of dementia, with some of these symptoms typical of specific types of dementia such as Fronto-temporal dementia, Dementia with Lewy Bodies and Dementia in Parkinson's Disease.

2.4.3 Physical issues, inter-current infections and comorbid conditions

One of the key impacts as dementia progresses is the increasingly physical nature of the illness - the frequency and severity of ill health is likely to intensify. Advanced dementia presents a range of potential symptoms that impact on mobility, bodily function, resilience and physical wellbeing (Alzheimer Scotland 2015). In addition to this older people are more likely to have other conditions and sensory impairments such as reduction or loss of hearing and sight. Many of the manifestations of advanced illness can be seen as resulting from a complex interplay of increasing cognitive impairment and diminishing physical robustness (Alzheimer Scotland 2015).

Age is the biggest risk factor for both pain and dementia (Alzheimer Scotland 2015). The presence of pain has been shown to be high in advanced dementia and increasing as death approaches. Inter-current infections^f are frequent in advanced illness as a result of such factors, reduced immune response and swallowing difficulties. Dementia is the greatest underlying risk factor for delirium^g, as dementia progresses, the risk of delirium increases (Vasilevskis et al 2012).

An untreated physical condition is a common cause of distress – this will become more acute as the person may become unable to interpret and express the location of physical pain (NES 2012). This relies upon the ability of those caring to recognise and interpret the signs of distress such as facial expressions, movements, behaviours and vocalisations (Alzheimer Scotland 2015).

The person with dementia becomes less able to advocate for themselves and report symptoms as the illness progresses. This can result in stress and progress to distress where the condition remains undetected and the person utilises whatever method is available to them to communicate their discomfort, pain and unmet need.

2.4.4 End of life in dementia

Not everyone reaching the end of life with dementia will be at an advanced phase of the illness. People can become terminally ill at any time during dementia because of the presence of other illness. There is likely to be the presence of pain and other distressing symptoms at the time of end of life (Alzheimer Scotland 2015).

There is a great deal of uncertainty in understanding when a person with dementia is dying. The person may continue to be mobile at this time. Delirium and terminal restlessness can occur near death when the person can become restless and agitated (Alzheimer Scotland 2015).

f A disease that intervenes during the course of another disease and can alter the course of the underlying disease (dementia).

g Delirium is an acute condition resulting from medical conditions including dehydration, constipation, pain and the effect or withdrawal of some medications. Delirium has a profound impact on brain function resulting, amongst other things, in disorientation, stress and distress.

2.5 Recognising individual needs within the social environment

The experience of dementia will be unique to every individual, determined by the interrelationship of the biological, psychological and social factors. Kitwood (1997) presented this complex interaction as the combination of five factors^h that will be unique to each person. These factors along with the influence of the social and physical environment will shape how the person experiences dementia.

Spector and Orrell (2010) develop this biopsychosocial understanding in providing a model to identify what factors may be responsive to changeⁱ and those which are fixed^j. The adaptable factors are important in minimising stress and preventing the occurrence of distress. Stress and distress can occur at any stage throughout dementia and can be transient.

Whilst the person's personality and way of coping endures throughout dementia, factors such as the characteristics of the different types of dementia and communication difficulties can have an influence (NES 2012). How the person expresses stress and distress can alter over the course of the illness as a result of these factors.

Stress and distress can be displayed in active behaviour including repeat questioning, continuous walking and shouting. It can also be expressed in subtle non-active ways such as the person becoming withdrawn and disinterested. An understanding of the person and knowing how they express both contentment and discomfort will be important in recognition of unmet needs (Brown 2018).

The increasing cognitive impairment that accompanies advancing dementia can have a devastating impact on human interaction. People with dementia can become stressed in the absence of supported social connection and activity. The responses of others are of key importance in keeping people with dementia in our shared world. Seeing the person merely through the prism of dementia will result in this being viewed as the basis for the interpretation for all their actions (Sabat 2010).



Source: Kitwood (1997)

Kitwood (1997) presented six psychological needs that are shared by everyone: 1) attachment 2) identity 3) occupation 4) inclusion 5) comfort and 6) love. People with dementia will increasingly come to rely on other people to support the fulfilment of these needs. When people's needs are not met, the most common emotions are anger, depression and anxiety (James and Jackman 2017).

Contextual, environmental and social factors will have an impact on both the creation and prevention of stress and distress. Factors such as level of noise and lighting become very important to wellbeing when the person with dementia is no longer able to make or request changes to their environment to suit their needs. There is potential within the social and physical environment to create a supportive and enabling space for the person with dementia.

h Personality/resources for action + biography + health + neurological impairment + social psychology = experience of illness

i Including physical health, mood, mental stimulation and environment

j Such as personality traits and health prior to dementia

2.6 Impact on and influence of those providing care

Many instances of distressed behaviour will be linked to interactions with other people. Specifically, this will relate to: 1) preventing the person with dementia from doing something that they want to and 2) attempting to get the person with dementia to do something they are reluctant to (Brown 2018). This can also occur when there are repeated corrections or contradictions from those providing care. This presents the approach of those providing care as the key to reducing the occurrence of stress and preventing distress (James and Jackman 2017).

There is evidence to support the effectiveness of family carer training and education strategies (Trivedi et al 2018). However, there can be a lack of awareness of information and support available and family carers can feel the situation is not evident to professionals until a crisis point has been reached (Braun et al 2018).

When the person continues to live at home much of their care is likely to be provided by those closest to them^k. Care workers will provide the day-to-day caring when the person is living in a care home. It can be difficult for those providing care to know how to respond to stress and distress. The expression of distress by the person with dementia can also be upsetting and stressful for those providing care. Those providing care can experience strong emotions in response to the care they are giving and the person they are giving it to. There is a need for emotional as well as practical support for family members, friends and professional carers.

The perception of stress in dementia is subjective and people will respond differently. What is perceived to be distressing behaviour by one person may not be by another. There may be situations where the stress may relate to the carer's own emotional experience, rather than the person with dementia (NES 2012).

The behaviour of the person with dementia is not necessarily something that needs to be stopped (Brown 2018). It may be most appropriate to find ways for the person to continue to express themselves through behaviour in a way that is safe and can be supported by the environment.

The person with dementia will be affected by the emotional response of others. The carer interactions can act to alleviate or possibly exacerbate emotional or physical stress and distress with the way in which they respond and their approach to caring.

The response of others will also be influenced by the relationship to the person with dementia. A close family member, such as the spouse, will have a very different emotional response to that of a care worker who did not know the person previously. The family carer will have gone through change and loss throughout the course of illness. Their own physical and psychological health may have deteriorated (Alzheimer Scotland 2015).

^k This is often the spouse, partner, adult children or other close relationship

2.7 Evidence on responses and interventions

There are five treatment approaches that guide the intervention adopted in responding to stress and distress in dementia (James and Jackman 2017). These are 1) care practices 2) environment modification 3) psychological and specific interventions 4) screening and treatment for a physical or mental health condition and 5) pharmacological therapeutic interventions. The strategy adopted should be guided by the principle of most appropriate and least intensive solution that responds to the practical, physical, emotional and spiritual needs of the person (British Psychological Society 2013).

Some of the psychosocial approaches have been shown to have a similar evidence of impact to pharmacological approaches, but without the risk of adverse events. However, the effectiveness of psychological approaches is dependent on how they are delivered and that they are tailored to the needs of the individual (James and Jackman 2017). This highlights the need for specialist practitioners to provide education and support to carers in implementing caring strategies.

There is a need for further research on many of the non-pharmacological strategies to assess their effectiveness as treatments (Braun et al 2018, Dyer et al 2017, Trivedi et al 2018).

Functional analysis^l based interventions has the strongest evidence of effectiveness (Dyer et al 2017). There is some evidence to support music therapy and pain management (Dyer et al 2017). There is also evidence to support the effectiveness of family carer training and education programmes in responding to stress and distress in people with dementia who are living at home (Trivedi et al 2018).

Whilst a non-pharmacological approach should be adopted whenever possible, medication does have a key role in treating some of the underlying causes of distress such as infection, delirium and pain (James and Jackman 2017). The use of psychotropic medication^m to manage distress has received significant attention because of concerns about inappropriate prescribingⁿ and the adverse effects. However, these drug treatments have a role in some instances such as responding to severe or persistent depression. They can have a role where there is distressing and severe psychotic symptoms, when there is risk of harm to the person with dementia or others.

Guidance (NICE 2018) recommends that antipsychotic medication should only be used for people with dementia who are either 1) at risk of harming themselves or others or 2) experiencing agitation, hallucinations or delusions that are causing them severe distress. It is also important that all other strategies have been explored.

Medication should be targeted at a low dose and increased if necessary according to individual response to targeted symptoms, aiming for the minimum effect for the minimum amount of time. Symptoms of stress and distress can occur at any stage of dementia and can be transient. Medication, particularly antipsychotics, should be kept under regular review and reduced and stopped where possible.

^l Functional analysis explores the meaning or purpose underlying the person's behaviour

^m This includes antipsychotic medication, sedatives and anti-depressants

ⁿ This includes being prescribed for sedative affects or for longer than is medically appropriate

2.8 Conclusion

Stress and distress in dementia has been shown to stem from the complex interaction of biopsychosocial and environmental factors and the impact this has on the person's thoughts, beliefs, emotions and behaviour. The importance of an individual response that recognises the holistic experience of the person has also been highlighted.

The key factor in alleviating stress and preventing distress in dementia has been identified as the recognition and the caring approach adopted by carers which is underpinned by the provision of education and support from specialist practitioners.

The following section will outline approaches, principles and those involved in delivering responses to stress and distress in dementia.

Section 3:

Responding to stress and distress in dementia

3.1 Introduction

The previous section outlined the nature and complexity of stress and distress in dementia. It highlighted the importance of a preventative approach based on the biopsychosocial needs of each individual.

This section presents the core principles and preventative approach in responding to stress and distress in dementia. It brings together the evidence base and good practice. The principles of the approach outlined below is appropriate when the person is at home, in a care home or an acute, community or specialist hospital.

3.2 Principles of approaches for the person and those caring in dementia

What

The principles that underpin approaches in responding to stress and distress in dementia are of key importance. The person remains the same equally valuable person throughout the course of the illness.

It should be recognised that not all stress will be solely or a direct result of the disease process.

Approaches should honour personhood and the right to be treated as a unique individual. The citizenship of the person with dementia should be recognised and their human rights respected, protected and fulfilled.

It is important to get to know the person, their potential triggers for stress and distress and to develop risk reduction and coping strategies.

The perspective and subjective experience of those providing care, including family, friends and professional carers, is integral to responding to stress and distress in the person with dementia. They will have the greatest insight to the person and their potential triggers. They will also have their own need for support.

Symptoms of stress and distress may alleviate on their own – when they do not, it is important that there is early intervention to consider the support needs of the person with dementia and those caring.

The distinction between prevention and treatment is also of crucial importance.

How

The strategy adopted should be guided by the principle of most appropriate and least restrictive solution that responds to the practical, physical, emotional and spiritual needs of the person.

The foundation of the approach should be preventative action that responds to moment-to-moment experiences and recognises the needs of the individual for comfort, activity and social connection. This should include an appreciation of how the person interacts within the context of the social and physical environment.

There should be an understanding of how contentment and stress or distress is expressed by the person. Knowledge of potential triggers for the person are important in recognition, initiating early responses and acting to decrease the occurrence of distress.

It is important that there is a proactive approach to ensure those providing care in dementia are aware of the sources of support and information available. There should be a recognition of the needs of those who are providing care.

There is a need for practical assistance in responding to the situation and strategies for managing their situation and strategies for managing the stress of those caring, including family, friends and professional carers. The health and wellbeing of those providing care should be considered independently of the person with dementia and their needs recognised and responded to.

No one individual will have the answer and it is important that there is meaningful engagement and collaboration between family, carers and specialist health and social care practitioners (Brown 2018) The complexity of stress and distress in dementia requires that this support is multi-disciplinary and co-ordinated (Alzheimer Scotland 2015).

3.3 Responding to the stress of living with dementia

What

During the post-diagnostic phase people with dementia and those closest to them will require a range of information and support to assist them to come to terms with the diagnosis, respond to stress and maintain wellbeing. Each family unit will have their own specific set of needs – it is therefore important that responses are holistic and individual.

Support will be required in responding to stress during the period of self-management as families adapt to living with dementia. As the illness progresses there is likely to be an increasing need for practical and emotional support, which will in turn influence the stress experienced by the person and those caring.

How

The key areas where support is likely to be required was evidenced by the Alzheimer Scotland Facing Dementia Together project (2012)^o. These five pillars have been adopted by the Scottish Government (2013) in providing a guarantee that people receiving a diagnosis of dementia would be offered a minimum of one year of post-diagnostic support based on the five-pillar model approach. This approach provides the mechanism for working with the person and those closest to them to identify the needs during the post-diagnostic phase.

As the illness progresses it will be important that community support is planned and coordinated in order to maintain wellbeing, quality of life and respond to stress and distress (Alzheimer Scotland 2012). It will be important to support personal coping strategies for the person with dementia and those close to them.

For some people with dementia and family carers, the shared understanding provided by others living with dementia will be central to adjustment and adaptation. This can provide the opportunity to relate to a shared experience and validation of the stresses experienced. For others opportunity for one-to-one therapeutic approaches such as counselling may be more beneficial. There are a range of psychological, social and practical supports for the early phase of dementia, the relevance of which will be dependent on individual needs (British Psychological Society 2014).

^o 1) Understanding the illness and managing symptoms 2) supporting community connections 3) peer support 4) planning and future care and 5) planning for future decision making.

3.4 The role of communication and activity in supporting prevention

What

Approaches to communication that respond to individual needs will be key, as people will differ in their ability to convey their needs and interpret their environment. A recognition of the impact of the two-way process of communication and how people with dementia can be affected by the emotional responses of others is also important.

People with dementia will continue to have a need for activities they will enjoy and social stimulation throughout the illness. Moment-to-moment experiences are a vital component of wellbeing and human interaction and social connection is important to preventing stress and distress. The engagement in everyday activities that are meaningful to the person and connections to the wider community can help people with dementia remain socially connected.

How

Whilst the person may no longer be able to use words to communicate, other forms of expression will be found and this calls on the resourcefulness and creativity of those around the individual to tune into these messages. Broader approaches to communication will be important to honour personhood, recognise the needs of the person and ensure they remain in our shared world. Successful communication can prevent distress – it will therefore be important to acknowledge and respond to non-verbal signs and cues from the person with dementia.

Approaches such as reminiscence therapy, life story work, Enhanced Sensory Day Care, Adaptive Interaction and music therapy were highlighted through the consultation process on developing the Advanced Dementia Practice Model (Alzheimer Scotland 2015). These techniques and approaches were used by dementia practitioners in understanding who the person is and identifying appropriate approaches to social connection and occupation.

The skill of delivery and tailoring to the individual needs are of key importance to the effectiveness of therapeutic interventions (James and Jackman 2017). There is a need for carer education, training and support from specialist practitioners in delivering these psychosocial strategies. This includes allied health professionals, psychologists, psychiatrists and nurses.

3.5 Responding to social and environmental factors

What

As stress and distress can often be triggered by external influences, contextual factors have a key role in both preventing and alleviating distress. This includes the physical environment and social and caring interactions.

Understanding needs within the context of the environment will become more important as the illness progresses and the person becomes less able to advocate for themselves. Understanding and responding to the person with dementia's insight and own sense of reality will be important, particularly where this differs to those around them..

Each person with dementia will interact with the environment and social context in a unique way. This will be shaped by such factors as life experience, personality, preferences, physical health and emotions. This means that there will be a wide range of potential triggers of stress and distress that will require an individualised and holistic approach.

How

Those providing care will be of key importance in identifying and responding to triggers within the social and physical environment and during caring interactions. The family, friends and carers are delivering these moment-to-moment interventions with their caring, understanding of the person and recognition of needs.

Specialist practitioners will be required to provide support and guidance to deliver person-centred responses that aim to alleviate stress and distress. This includes allied health professionals, psychologists, psychiatrists and mental health and acute nurses.

The symptoms of stress may alleviate on their own at times. When they do not, monitoring the situation will be important to identify patterns and develop a recognition of potential triggers.

Within a 24-hour care setting, such as a care home or hospital, there is opportunity to take note of the behaviour throughout this time frame to recognise the cycle of stress and identify points of intervention to maintain balance and act with preventative measures to promote wellbeing and quality of life.

3.6 Detection and treatment of physical and mental health factors

What

The biopsychosocial nature of dementia outlined in section 2 of this report highlights the importance of a health assessment to detect and treat underlying psychological and physical causes and risks.

Identifying and treating illness and potentially reversible^p mental and physical conditions will enhance wellbeing, comfort and quality of life.

How

Health care practitioners provide the key role in responding to the complex physical and psychological symptoms that can occur in dementia and in other underlying and co-morbid health conditions. This requires a coordinated and planned approach that is multi-disciplinary to ensure the required practitioners provide timely responses to physical and psychological health conditions that occur.

When the person is living in the community^q the local primary care practice or community mental health team for older people is likely to be the initial response. Where the person is in hospital^r it is important that this physical and psychological care is provided as part of a holistic approach to treatment (Alzheimer Scotland and Scottish Government 2018). Psychiatry of old age liaison teams also play a pivotal role in the assessment and management of people with dementia admitted to acute and community hospitals.

The practitioners required to support physical and psychological health conditions include primary care staff, mental health practitioners^s and allied health professionals.

Palliative care specialists will also be important in providing guidance on pain and other distressing symptoms.

This approach can provide timely responses to physical and psychological health conditions to promote quality of life, comfort and psychological wellbeing.

Where possible, care and treatment should be provided for the person within their current location avoiding unnecessary hospital admission.

There is a need for health care practitioners to support those providing care through education on appropriate approaches to care and responding to the complex physical conditions that can arise in dementia. It is also important to learn from the experience and understanding of those providing care.

p This includes physical issues such as pain, infection, delirium or negative impact of medication and psychological conditions such as depression and anxiety.

q Living at home or in a care home

r Acute, community and specialist dementia hospital care

s Mental health nurse, psychology and psychiatry

t Including speech and language therapist, dietitian, occupational therapist and physiotherapist

3.7 Specialist-led approaches and functional analysis

What

A more structured method will be required in responding to stress and distress where the situation is complex and the symptoms have not been alleviated by the approaches previously outlined.

Whilst they will be led by practitioners who have received specialist training in the method, the expertise of families and those providing care will be crucial to supporting and delivering these processes.

They also require the engagement and inclusion of those providing care to draw insight from their understanding of the situation and respond to their own need for recognition and support.

These methods also rely upon information, knowledge and understanding gathered from the initial attempts to respond to and ease the stress and distress. Whilst this approach is for complex situations, the measures implemented are not by definition intensive interventions (James and Jackman 2017).

The process of review and analysis of the situation can result in a care plan that calls for simple and easily implemented caring strategies and environmental modifications.

How

High-intensity approaches focus on the specific needs and issues that arise in dementia, such as communication, memory and interpersonal interactions (British Psychological Society 2013).

They include structured protocols such as Dementia Care Mapping (Bradford Dementia Group)^u and Treatment Routes for Exploring Agitation (TREA) (Cohen-Mansfield 2000).

The TREA approach considers what unmet need may trigger the behaviour being expressed, how the behaviour results from the need^v and what intervention would be appropriate to meet the need. The aim of the approach is to enhance the quality of life of the person with dementia and reduce the stress on those providing care (Cohen-Mansfield 2000).

Functional analysis and formulation-led approaches use specific psychological frameworks to understand the experience and needs of the individual (British Psychological Society 2013). This includes the Newcastle Model (2011) that builds from seeking to understand the person's perception of reality in relation to their current circumstances and how closely that matches that of the social context and the present environment (James 2011).

The biopsychosocial approach^w seeks to develop a theory on why the person is experiencing distress and devise an intervention to address the underlying cause and measure its effectiveness. This can be used when no one single factor alone is likely to remedy the situation and it is necessary to piece together a picture to formulate understanding, reviewing as required as circumstances alter and new understanding comes to light.

The carer is the key factor in resolution, therefore the practical nature and realistic application of any intervention following on from the process is key to the success (James and Jackman 2017).

^u Within the context of a 24-hour care environment such as hospital or a care home, it provides a cyclical approach to assessing and reviewing the ongoing needs of the individual, carer and environment. It includes person-centred care planning, staff training needs and monitoring and implementing improvements to care and the environment.

^v Does the behaviour being expressed accommodate the need (e.g. occupation, stimulation, exercise) or does it express the need (e.g. discomfort, pain, boredom) – in the former instance, the aim would be to provide a safe and manageable method for the behaviour to be accommodated.

^w The framework considers a wider range of factors including the person's background, mental and psychological health, personality, appearance and social environment. It includes reflection and revision of the effectiveness of strategies and new insights that may emerge.

Section 4: Conclusion

This report has highlighted the distinction between stress and distress. Whilst stress is a common human emotion, distress describes an extreme occurrence of physical and psychological suffering. A preventative approach based on holistic good practice will assist in responding to needs and reduce the escalation of stress.

An understanding of the nature of stress and distress in dementia is fundamental to everyone providing care in dementia. It is important that there is a coordinated and multi-disciplinary response that is based on the unique needs of the individual and their carers. Understanding the person and how they express both contentment and discomfort will also be of key significance.

Important principles in responding to stress and distress in dementia:

- Promoting Excellence Framework is the basis for evidence-based care for all practitioners
- Responses to stress and distress are underpinned by the Charter of Rights for People with Dementia and their Carers, Promoting Excellence Framework, the AHP framework for Connecting People, Connecting Support, 5 Pillars Model of Post-Diagnostic Support, 8 Pillars Model of Community Support, Advanced Dementia Practice Model, Transforming Specialist Dementia Hospital Care, 10 Dementia Care Actions in Hospital, and Standards of Care for Dementia in Scotland.
- A planned, coordinated approach to supporting the person with dementia and those providing care to ensure emotional and practical support and guidance in responding to stress and distress.
- The subjective experience and needs of the person with dementia and of those providing care is understood and responded to.
- Prevention is the foundation of the approach through meeting the individual need for comfort, activity and connection.
- Where stress and distress is present, the underlying guiding principle is the most appropriate and least restrictive solution that responds to the practical, physical, emotional and spiritual needs of the person.
- Any intervention should be reviewed frequently and only used for the minimum time necessary.

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Understanding stress and distress in dementia: the importance of a person- centred preventative approach

Stress and distress can occur throughout dementia and is not necessarily solely or directly related to the illness. It can have a wide range of underlying causes that reflect the unique experience of the person within the context of their environment.

This report provides an understanding of the nature of stress and distress in dementia. It also outlines responses based on evidence and good practice. The purpose of this report is to provide knowledge and understanding to a wide audience and to add value to current good practice and resources.



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