Coping with the Disease

Family and Societal Perspectives
(Neurology and medical care of neurodegenerative disorders)

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Intended Learning Outcomes

At the end of this lesson the students should be able to:

- Explain the tenets of good communication with family members
- Interpret the reactions of the family towards the diagnosis
- Recognize the importance of 'balanced education' about the disease
- Explain strategies of planning an appropriate living environment for a person with NDD
- Outline the partnership in own care model
- Discuss the impact of early onset dementia on children

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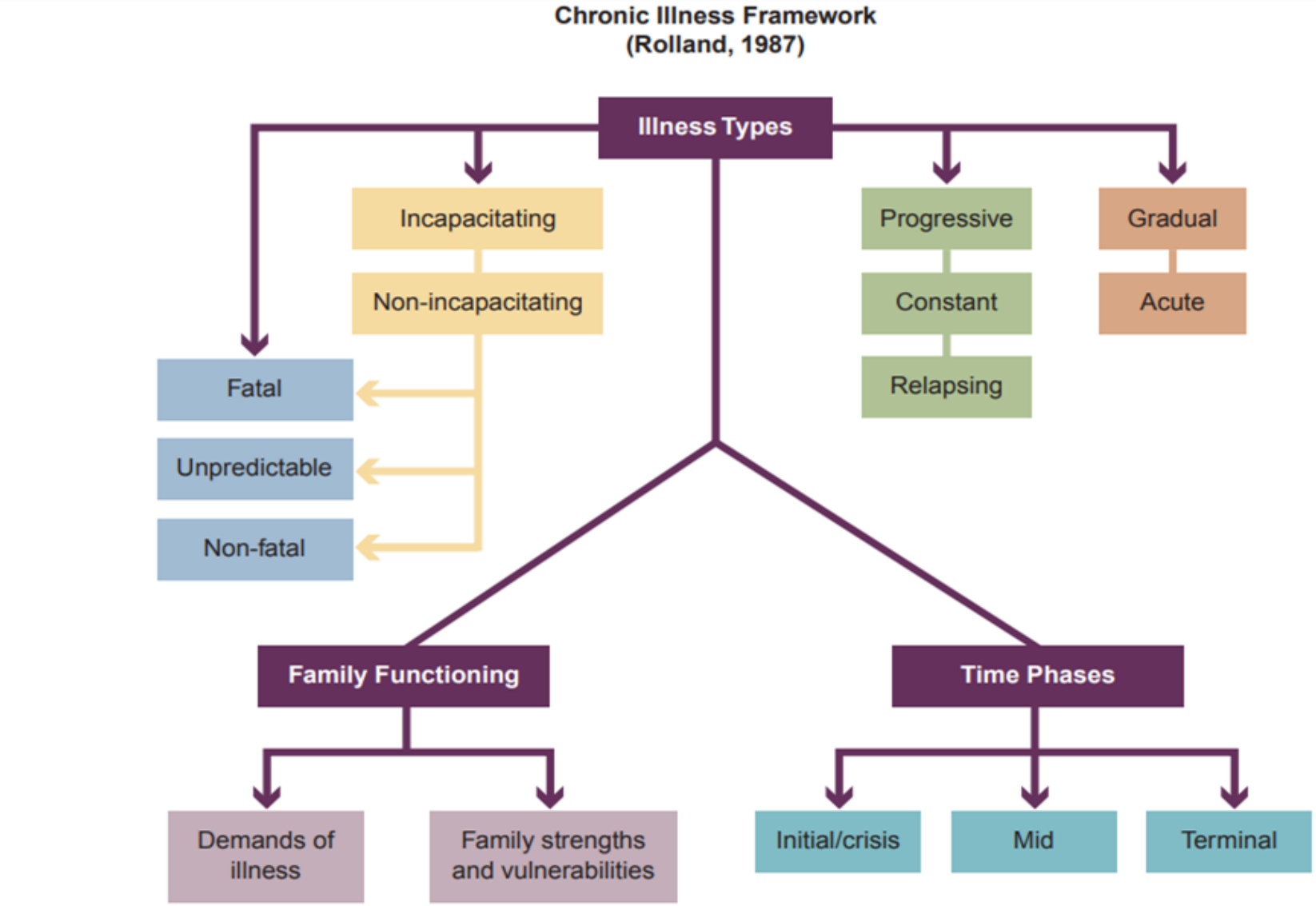

FIGURE 3-7 Family systems and illness model.

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Family Assessment and Intervention Model

According to this model, families are viewed as

- A dynamic, open system interacting with their environment.
- One of the roles for families is to help buffer their members, or protect the family as a whole, from perceived threats to the family system.
- The core of the family system comprises basic family structure, function, processes, and energy/strength resources.
- This basic family structure must be protected at all costs, or the family ceases to exist

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Family Assessment Intervention Model

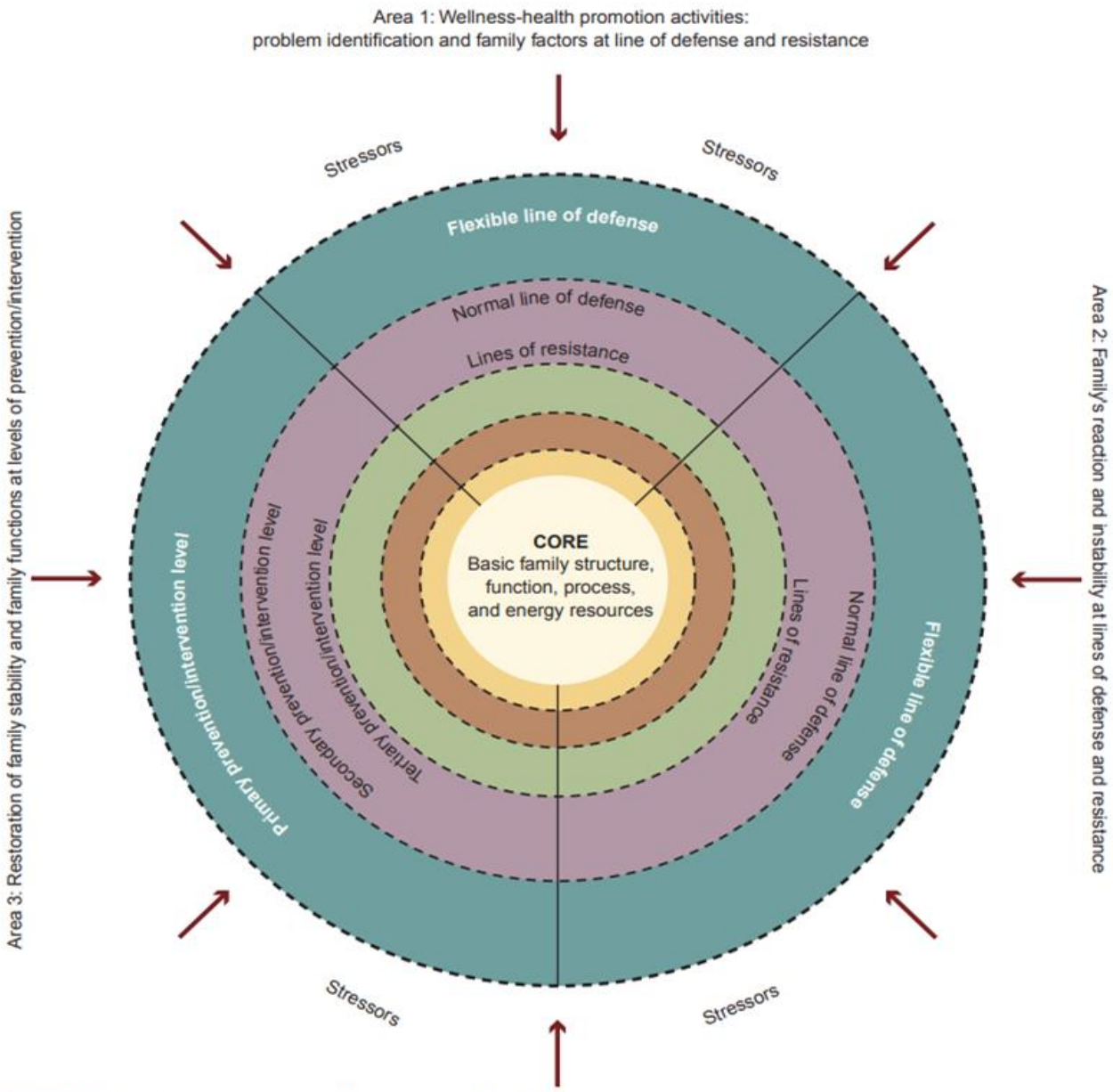

FIGURE 3-8 Family Assessment and Intervention Model.

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BOX 3-1

Basic Assumptions for Family Assessment and Intervention Model

- Although each family has a unique family system, all families have a common basic structure that is a composite of common, known factors or innate characteristics within a normal given range of response.
- Family wellness is on a continuum of available energy to support the family system in its optimal state.
- The family, in both a state of wellness or illness, is a dynamic composite of interrelationships of variables (physiological, psychological, sociocultural, developmental, and spiritual).
- A myriad of environmental stressors can affect the family. Each stressor differs in its potential for disturbing the family's stability level or normal line of defense. The specific family interrelationships (physiological, psychological, sociocultural, developmental, and spiritual) affect the degree to which a family is protected by its flexible lines of defense against possible reactions to the stressors.
- Families evolve a normal range of response to the environment, which is called a *normal line of defense*. The normal line of defense is flexible or accordion-like as it moves to protect the family.
- When the flexible line of defense is no longer capable of protecting the family or family system against the environmental stressor, the stressor is said to break through the normal line of defense.
- Families have an internal resistance factor called the *line of resistance* that functions to stabilize and return the family to its usual wellness state (normal line of defense), or possibly to a higher level of stability after an environmental stressor reaction.
- Primary prevention is general knowledge that is applied in family assessment and intervention for identification and mitigation of risk factors associated with environmental stressors to prevent possible reaction.
- Secondary prevention is symptomatology after reaction to stressors, appropriate ranking of intervention priorities, and treatment to reduce their noxious effects.
- Tertiary prevention is the adjusting processes that take place as reconstitution begins and maintenance factors move the client back in the circular manner toward primary prevention.
- The family is in a dynamic, constant energy exchange with the environment.

Adapted from Berkey, K. M., & Hanson, S. M. (1991). *Pocket guide to family assessment and intervention.* St. Louis, MO: Mosby–Year Book.

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Discussion: Guided Reading

1. What are the tools that can be used when assessing the family?
2. What are the records that students/ nurses must keep?
3. How to develop a family careplan?

			Prevention/Intervention Mode		
Diagnosis: General and Specific Family System Stressors	Family Systems Strengths Supporting Family Care Plan	Goals for Family and Clinician	Primary, Secondary, or Tertiary	Prevention/ Intervention Activities	Outcomes Evaluation and Replanning
Dx of MS weakness of swallowing, pain, vision impairment, vertigo/tinnitus, constipation, urinary infections, guilt/anxiety, depression, sexual dysfunction, over-load for caregiver father.	Couple communication, religious faith, social support of extended family, good medical care.	Restoration of stability and homeostasis at each level of progressive chronic illness.	Support of family changes, connect family with MS family support group, locate part-time family helper for home, coordinate with other medical groups involved, set up rehabilitation, and physical therapy.	Couple receives counseling, pain and symptom management; involve social worker to look at community agencies to offer assistance.	Evaluation to be done once plan implemented.

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What is Person Centred Care? The Theory:

- **Patient empowerment** - that is, giving patients the tools to look after and be responsible for their own illness or condition

- **Shared-decision-making** - that is a situation where clinician and patient work as equal partners in a Patient Centred Care driven context

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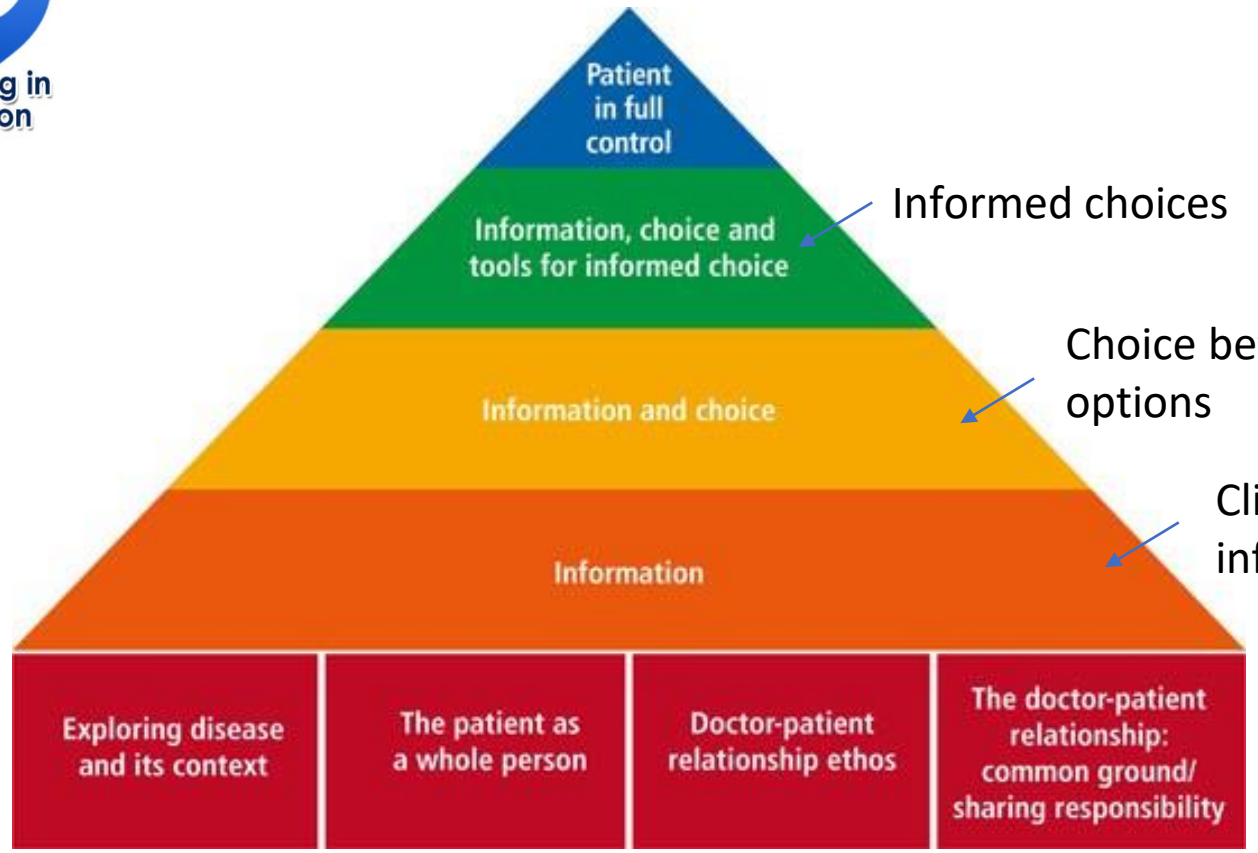
What is Person Centred Care?



Informed choices

Choice between treatment options

Clinician providing basic didactic information to patient

Priniciples of good care

Defining patient-centred care in dentistry - A systematic review of the dental literature
S Scambler, M Delgado, K Asimakopoulou - British dental journal, 2016

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Enabling individuals to actively participate in their care

Many people wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions.

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Good practice suggestions - Communication

- Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.
- Maximise participation in communication by, for example:
  - maintaining eye contact with the patient (if culturally appropriate)
  - positioning yourself at the same level as the person/family you are talking to
- Ensure that the accent, use of idiom and dialect of both individual/family and the healthcare professionals are taken into account when considering communication needs.
- Avoid using jargon. Use words the family will understand, define unfamiliar words and confirm understanding by asking questions.
- Use open-ended questions to encourage discussion.
- Summarise information at the end of a consultation and check that the patient has understood the most important information.

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National Institute for Clinical Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: Clinical Guidelines (CG138). London: NICE; 2012

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Good practice suggestions – Information provision

- Give the family information, and the support they need to make use of the information, in order to promote their active participation in care and self-management.
- Explore the family'spreferences about the level and type of information they want. Based on this, give the individuals (and their family members and/or carers if appropriate) clear, consistent, evidence-based, tailored information throughout all stages of their care. This should include information on:
  - their condition (or conditions) and any treatment options
  - where they will be seen
  - who will undertake their care
- Give the individual (and/or their family members and carers) information to enable them to use any medicines and equipment correctly.
- Advise the fgamily where they might find reliable high-quality information and support after consultations, from sources such as national and local support groups, networks and information services.
- Give the family regular, accurate information about the duration of any delays during episodes of care.

National Institute for Clinical Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: Clinical Guidelines (CG138). London: NICE; 2012

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Breaking bad news – some guidiance

- The ability to “break bad news” to patients and families is a key communication skill.
- Many practitioners view breaking bad news as a communication skill that is important for clinicians working in end-of-life care, where the news can be that treatment has been unsuccessful leaving few options for disease control, or that death is imminent.
- Bad news can be understood as any information that changes a person’s view of the future in a negative way.- The practitioner cannot judge what constitutes bad news and should be aware of this with any news that has the potential to alter an individual’s view of themselves or their future.
- Nursing practice does not regularly include the diagnosis of a life-ending illness, but often involves the communication of news that a new chronic diagnosis is present, that a chronic illness has worsened, or that attempts at management through medication or nonpharmacologic interventions have not been effective and that a new course of treatment is necessary.

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The SPIKES* Protocol

- There are several accepted ways to break bad news. These methods include using common formats of structured listening to what the patient knows and wants to know, giving information in understandable amounts, reacting to the news, and checking for understanding.

- The SPIKES Protocol is a common template for breaking bad news that NPs can utilize as a starting place if they are unsure of how to proceed.

- The acronym SPIKES, stands for **S**etting up, **P**erception, **I**nvitation, **K**nowledge, **E**motions with Empathy, and **S**trategy or Summary.

** Designed by* *Walter Baile and colleagues at the University of Texas MD Anderson Cancer Center in Houston Texas, USA*

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SPIKES protocol explained

1. Establish an appropriate setting.
2. Check the patient's perception of the situation prompting the news regarding the illness or test results.
3. Determine the amount of information known or how much information is desired.
4. Know the medical facts and their implication before initiating the conversation.
5. Explore the emotions raised during the interview.
6. Respond with empathy.
7. Establish a strategy for support

Further Reading: *Breaking bad news: A guide for effective and empathetic communication Margaret Quinn Rosenzweig, PhD, FNP-BC, AOCNP, assistant professor https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5578619/*

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Balanced information giving

Patients and families often need to process their feelings and are often unable to take in any other information immediately after being told the diagnosis

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Coping with a diagnosis – for the person and for their family

https://www.dementiauk.org/wp-content/uploads/2020/08/emotional-impact-of-the-diagnosis.pdf

- People vary as to how they accept the diagnosis of dementia. For some, there is a degree of relief, as they now understand what is happening to them. But sometimes, their friends and family do not share this sense of relief, and this can cause communication issues.

- Some families have difficulty accepting the diagnosis and the changes dementia can cause. This can be particularly true if the person's symptoms do not seem to be what is commonly expected of dementia

- In some types of dementia, particularly frontotemporal dementia, the symptoms appear as changes to the person's personality or the way they behave, with memory problems occurring very much later on.

- Younger people, or those with less obvious symptoms, can sometimes receive comments such as: "It can't be dementia, you remember everything about things that happened a long time ago", or "You can't have dementia; you're too young", or even: "They seem alright to me". These comments can cause distress to the person living with the condition and their family.

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After a diagnosis of dementia -family and friends

https://www.dementiauk.org/wp-content/uploads/2020/08/emotional-impact-of-the-diagnosis.pdf

- In many cases, those who are diagnosed with dementia and their family accept that the diagnosis will alter the way they will live their lives.

- However, not all family members feel able to take part in these discussions and decisions. Even within the closest family there can be disagreements about what is best for the person living with dementia, and this can lead to communication and relationship issues.

- Some people feel embarrassment or shame about their diagnosis, and may withdraw themselves from their family and friends. Similarly, some family members of a person diagnosed may feel ashamed or embarrassed, and may begin to cut themselves off socially.

- Withdrawing socially can lead to feelings of isolation and hopelessness, and can have a negative impact. If the news about the diagnosis is shared with others, and social connections with friends and family are maintained, this can have a positive effect on the emotions and well-being of everyone involved.

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Impact on family members and caregivers

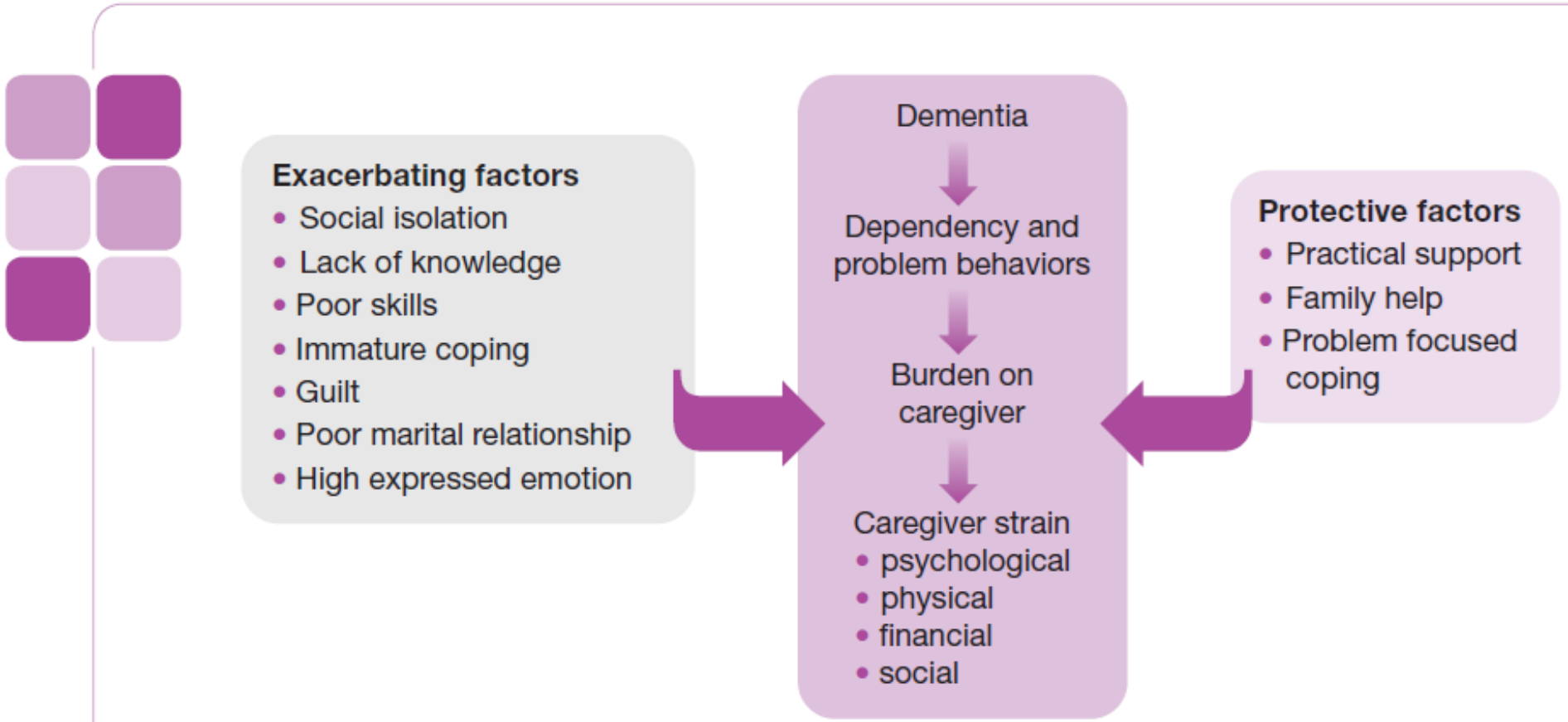

Figure 4.1: Model of effects of dementia on caregivers. Reprinted with permission from Brodaty (1997) and based on Poulshock and Deimling (1984).

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Protective factors – avoiding burnout

Family caregiver characteristics

- Informal supports (e.g., caring family, friends, neighbors)
- Knowledge about dementia, its effects, and management
- Mature coping skills (e.g., problem solving)
- Support groups (e.g., Alzheimer's Association)

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The Impact of Dementia on Children

- Dementia affects the whole family, and it is important to forget the impact it can have on children. Children will often experience dementia through contact with a relative (or the relative of a friend) who has dementia. This is usually a grandparent (or great-grandparent, as more people are living to their 80s or 90s), but it is also possible that one of their parents may develop young-onset dementia.

- Dementia can affect children in a number of ways. They may become aware of changes in the person and their relationship with the person altering. Perhaps a grandparent who gave them lots of attention and treats gradually becomes more inward looking and less inclined to make a fuss of them. Sometimes children may notice the person speaking or behaving in ways they find hard to understand

Dementia Support for family and friends Dave Pulsford and Rachel Thomson Second edition 2020

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Talking to children about Dementia

- The best approach is to be open with children about the fact that someone has dementia. How this is done will depend on the age of the child and the nature of their relationship with the person.

- It isn't usually necessary to go into much detail, but some books and online resources are available that aim to explain dementia to children and young people if they want to know more.

- Dementia UK has produced books for children https://www.dementiauk.org/about-dementia/young-onset-dementia/young-onset-dementia-resources/books/dementia-books-for-children/

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Environment

- Environmental comfort is a term that refers to the physical comfort of a person within a particular environment. This includes temperature, humidity, air quality, and lighting.

- The physical environment can work well – or create some big problems – for people living with dementia, whether it's in a person's own home or a care home. Assistive technology, developing dementia-friendly communities, understanding risk – all these issues play an important part in supporting people living with dementia.

Video: https://youtu.be/MRcd6xzUwKs

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Dementia Friendly Environment Checklist

Alzheimer's Society
United Against Dementia

Where possible, all events should be as dementia friendly and inclusive as possible. There are simple steps you can take to include everyone, from inviting your local care home, or Alzheimer's Society group, to making sure all signage is clear and there's not too much noise.

Below is a checklist to make your event dementia friendly. This list is not exhaustive, and you shouldn't be put off your event if you cannot tick them all off. If possible speak to people living with dementia and ask them how they find the area.

https://www.alzheimers.org.uk/sites/default/files/2019-01/Dementia%20Friendly%20Environment%20Checklist.pdf

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Environment design – an interactive guide

Go to the website- Click on one of the dots or the thumbnails below to learn more

https://www.healthdesign.org/tools/interactive-design-diagrams/outpatient-ambulatory-care-rooms/dementia-friendly-waiting-room#design-element--8

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