Government of **Western Australia**
Department of **Health**
Clinical Simulation Support Unit

Interprofessional Learning Through Simulation Project

Husband and wife are not coping – Interprofessional practice in community-based dementia care

Facilitators' Guide

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The filmed scenario has been developed from the experiences of the Interprofessional Learning in Simulation Project Steering Group. All due care has been taken to make the scenarios as realistic as possible. The characters in the filmed scenarios are fictitious and any resemblance to persons living or dead is purely coincidental.

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Contents

How to use this resource

This resource (the Facilitator's Guide) provides the framework to support the development of communication and problem solving, together with problem-based learning scenarios that encompass some challenging (but quite typical) patients that clinicians could expect to encounter as part of their practice. The goal of this interprofessional learning experience is to help prepare all health professionals – be they students or beginning clinicians – for working together.

The goal of this interprofessional learning experience is to help prepare all health professionals – be they students or beginning clinicians – for working together.

This resource is intended to develop your understanding of the principles of interprofessional practice and raise your awareness of opportunities for implementing interprofessional practice in your own environment. Throughout the resource are opportunities to consider how notions of interprofessional practice affect your current work practices and activities that enable you to reflect on these.

Interprofessional learning through simulation

This resource utilises simulation as a means to facilitate a learning experience; one that re-creates events that are closely linked to reality. Gaba[1] defined simulation as a technique, rather than a technology, to replace or amplify real life experiences with guided experiences, often immersive in nature, to evoke or replicate aspects of the real world, in a fully interactive pattern.

Simulation provides a safe learning environment for students to practice, where they are free to make mistakes, correct them and improve the processes of care.[2] Simulation is the bridge between classroom learning and the real life clinical experience, allowing students to put theory into practice.

Interprofessional learning through simulation provides learning opportunities to prepare future health care professionals for the collaborative models of health care being developed internationally[3] and can encompass a range of environments and resources that harness technologies, including multimedia and online applications.[4]

Resource contents

There are four sections within this resource. Information presented in Section One and Section Two is largely focussed on interprofessional learning and Section Two also contains an introductory section on interprofessional practice.

- Sections One and Two of this resource contain questions that require users to reflect on the content they have covered.
- Scenarios included in Section Three require users to watch the associated audiovisual resource ‘Husband and wife are not coping’ and complete the questions that relate to interprofessional learning in community-based dementia care.
- Section Four provides a literature review about interprofessional practice (IPP) in community-based dementia care which can be used as reference material.

Learning objectives

The key interprofessional learning message of this resource is:

Interprofessional practice (IPP) in community-based dementia care

The learning objectives of this resource are based on **five competency domains** from the Australian audit of interprofessional education in health:

- Teamwork;
- Understanding roles and respecting other professions;
- Role clarification;
- Understanding of Interprofessional Education (IPE); and
- Reflection.[5]

Learning outcomes will be addressed through the consideration and discussion of material presented in Sections One and Two in relation to interprofessional practice generally, and the case study presented in Section Three which is focussed more specifically on interprofessional practice (IPP) in community-based dementia care.

Learning outcomes

On completion of this resource, participants should be able to:

- Identify the key elements of interprofessional practice;
- Differentiate between interprofessional practice and current ways of working;
- Understand the importance of 'human factors' and appreciate how non-technical factors impact patient care;
- Develop an awareness of tools to enhance successful communication with patients and carers;
- Describe strategies to develop a deeper understanding of other professions' roles and responsibilities;
- Identify what changes are required to promote interprofessional practice;
- Distinguish between the roles of the health professionals involved in this case study, including areas of possible overlap;

- Identify the potential barriers to interprofessional communication and collaboration in the context of community-based care;
- Assess the impact of team communication and team relationships on patient care;
- Apply the ethical principles that guide all aspects of patient care and teamwork to this case study; and
- Reflect on own and other health professionals' practice.

Section One: What is 'interprofessional'?

Why the need for interprofessional learning?

In today's health care setting, human service professions are facing problems so complex that no single discipline can possibly respond to them effectively.[6] The World Health Organization (WHO) has stated 'It is no longer enough for health workers to be professional. In the current global climate, health workers also need to be interprofessional'.[7]

What does the term interprofessional mean?

Interprofessional learning (IPL) is defined as:

- Learning arising from interaction between members (or students) of two or more professions. This may be a product of interprofessional education or happen spontaneously in the workplace or education settings.[8]

Encourages professions to learn with, from and about each other

Interprofessional education (IPE) is defined as:

- Occasions where two or more professions learn from, with and about each other to improve collaboration and the quality of care.[8]

Interprofessional practice (IPP) is defined as:

- Two or more professions working together as a team with a common purpose, commitment and mutual respect.[8]

When interprofessional practice is working well it is thought to achieve the following six outcomes:[9]

1. **Works to improve the quality of care:**

   No one profession, working in isolation, has the expertise to respond adequately and effectively to the complexity of many users' needs and to ensure that care is safe, seamless and holistic to the highest possible standard.

2. **Focuses on the needs of service users and carers:**

   IPL puts the interests of service users and carers at the centre of learning and practice.

3. **Encourages professions to learn with, from and about each other:**

IPL is more than common learning, valuable though that is to introduce shared concepts, skills, language and perspectives that establish common ground for interprofessional practice. It is also comparative, collaborative and interactive, a test-bed for interprofessional practice, taking into account respective roles and responsibilities, skills and knowledge, powers and duties, value systems and codes of conduct, opportunities and constraints. This cultivates mutual trust and respect, acknowledging differences, dispelling prejudice and rivalry and confronting misconceptions and stereotypes.

4. **Respects the integrity and contribution of each profession:**

IPL is grounded in mutual respect. Participants, whatever the differences in their status in the workplace, are equal learners. They celebrate and utilise the distinctive experience and expertise that participants bring from their respective professional fields.

5. **Enhances practice within professions:**

Each profession gains a deeper understanding of its own practice and how it can complement and reinforce that of others. This is endorsed where the IPL carries credit towards professional awards and counts towards career profession.

6. **Increases professional satisfaction:**

IPL cultivates collaborative practice where mutual support eases occupational stress, either by setting limits on the demands made on any one profession or by ensuring that support and guidance are provided by other professionals if and when added responsibilities are shouldered.

How is interprofessional practice different to how people currently work?

The Australasian Interprofessional Practice and Education Network (AIPPEN) have identified a number of terms currently that convey a similar but different intent and meaning to the term interprofessional.[10]

Interdisciplinary

- Interdisciplinary has been used by researchers and practitioners when they attempt to analyse, synthesise and harmonise the connections between disciplines, to generate a coordinated and coherent health delivery system.[11] 'Interdisciplinary' is said to lack the inherent depth of collaboration implied by the term 'interprofessional'.

Multidisciplinary

- Health professionals represent a range of health and social care professions that may work closely with one another, but may not necessarily interact, collaborate or communicate effectively.[12]

Multiprofessional

- Work occurs when a range of professional practitioners work in parallel. Each discipline has clear role definitions and specified tasks and there are hierarchical lines of authority and high levels of professional autonomy within the team.
- Multiprofessional, as a term, may not imply optimal levels of collaboration.
- Practitioners consult individually with service users and use their own goals and treatment plans to deliver services.[13]

Collaboration

- Is ‘an interprofessional process of communication and decision-making that enables the separate and shared knowledge and skills of health care providers to synergistically influence the ways patient/patient care and broader community health services are provided’.[14]

Do we need to focus on interprofessional collaborative practice – don't professionals already work interprofessionally?

Interprofessional practice is a way of practicing that is based on collaboration. Nurses, doctors and other health professionals have, for a long time, worked closely together and have developed successful long-term partnerships. However, as has been stated:

> We cannot assume that health professionals have either the skills or attributes required for interprofessional practice. They may need to learn how to collaborate. Developing interprofessional practice requires a commitment to engage in shared learning and dialogue. Dialogue has the potential to encourage collegial learning, change thinking, support new working relationships, and improve patient care.[15]

Although health professionals receive extensive professional development, most training emphasises specific disease processes, technology and treatment and has largely undervalued human factors. Human factors training is necessary to help individuals learn how to improve working relationships with colleagues and those from other disciplines.[15]

The end goal of interprofessional education is to create a health workforce with improved levels of teamwork, collaboration, knowledge-sharing and problem-solving, eventually leading to better patient and patient outcomes in health settings.[16] The WHO has recognised the importance of interprofessional education and collaborative practice in developing a health workforce that is able to meet the complex health challenges facing the world and assist in the achievement of the health-related Millennium Development Goals.[7]

ACTIVITY ONE

What would you expect to notice as indicators of interprofessional practice?

What range of factors might be different in an interprofessional practice environment?

ACTIVITY ONE: ANSWER AID

Anecdotes from clinicians with an increasing awareness of interprofessional thinking and behaviour in the clinical environment:

“I went to a placement and something clicked. It gelled and I suddenly got it…it’s more than an awareness of others – you realise you are not an island and it’s up to others as well. You can recognise opportunities for clients and refer them to other disciplines”.

“I used to get frustrated at them not seeing through my discipline lens but then I saw how difficult it was for me to learn about their discipline”.

“You begin to realise you are part of a bigger picture and because of that you need to be able to communicate with people in a way they understand…I was listening to nurses with all the jargon they use and it made me become more aware of the amount of jargon I use – I thought I was practising interprofessionally but didn’t realise I was using so much jargon”.

Section Two: Competency framework for interprofessional education

Although a range of competencies have been identified, there is no one overarching framework that provides a definitive set of interprofessional competencies. Initial findings from an Australian national audit of pre-registration interprofessional education in health identified five IPE domains to support the development of a national curriculum framework. The identified domains were:

- Teamwork;
- Understanding roles and respecting other professions;
- Role clarification;
- Understanding of IPE; and
- Reflection.[5]

Patients will increasingly demand physicians, nurses and other health professionals to communicate and work together effectively

Teamwork

The identified domain 'teamwork' included the elements: communication; leadership; attitudes; team relationships; and conflict resolution. We know that effective teamwork plays a key role in improving quality and safety in health care, and the need for increased collaboration and teamwork across the health professions is necessary in order to care for an aging population with multiple chronic illnesses.[17] Patients will increasingly demand physicians, nurses and other health professionals to communicate and work together effectively. Teams bring their collective knowledge and experience to provide a more robust foundation for decision-making than any single clinician can offer.[17]

Team functioning and collaboration is thought to be enhanced when individuals:

- Participate in team activities;
- Foster positive team relationships;
- Appreciate differing personalities within teams; and
- Demonstrate respect.[17]

Lack of focus on human factors

The elements that make up teamwork are regarded as 'human factors' and are the non-technical factors that impact on patient care. Human factors can be defined as the interaction of equipment and individuals and the variables that can affect the outcome.[18,19] Bromiley and Reid quote Catchpole in their article[20], stating that more broadly the term clinical human factors can also encompass interactions with the environment that include an 'understanding of the effects of teamwork, tasks, equipment, workspace, culture and organisation on human behaviour and abilities, and the application of that knowledge in clinical settings'.

The contemporary focus of human factors in health care reportedly had its genesis in the work of James Reason in 1995 when he stated that, 'human rather than technical failures now represent the greatest threat to complex and potentially hazardous systems'.[21] More recent research highlights that rather than poor technical skill, human factors such as suboptimal communication and organisational system and culture inadequacies were implicated in up to 87% of the errors, adverse events and near misses that occur.[22-25]

Historically, health care has regarded technical skills and competence as key to patient safety. Technical excellence in, for example, nursing and medicine is important because health care professionals need to know what they are doing to maintain high standards of care and quality outcomes for patients. However, other safety-critical industries (such as defence and aviation) have learnt that even the most technically qualified and expert individuals can encounter difficulties when under stress. Such non-technical abilities – sometimes referred to as 'soft skills' – need to be valued equally.[26] Humans, when under pressure, have a capacity to become overly focused or fixated on technical problems.[27] Focus on human factors to improve the way teams work is important because:

- Opportunities to optimise the way teams work is becoming progressively more difficult with an increasing number of part-time workers, increasing patient loads and decreased staffing;
- The attitudes and behaviours of those who make up `teams' can be problematic at times and a lack of congruence in how teamwork itself is interpreted exacerbates underlying resentments, undermines professional esteem, and in some cases, creates outright conflict; and
- Working in teams at times can be fraught with difficulties and the `ideal' of effective team – working as defined in the prescriptive literature, is apparently rarely realised.[28]

ACTIVITY TWO

Think about your team (past or present) and how your team functions…what are the issues that make it challenging to focus on improving team performance?

What strategies have you found to be effective in improving team performance?

What do you feel could be done to improve team performance?

Communication

Appropriate interprofessional communication:

- Maintains patient confidentiality;
- Provides and delivers feedback;
- Promotes the role of other disciplines to patient/carers ;
- Communicates in a clear and concise manner;
- Acknowledges the knowledge and skills of other disciplines; and
- Minimises discipline specific terminology.

Interprofessional practice also places an increased focus on the needs of service users and carers. Although communication among and between professionals is critical, to ensure the interests of service users and carers remains at the centre of learning and practice, strategies to enhance communication practices with service users and carers are essential. Patient-centred care:

- Places the service users and carers at the centre of practice;
- Establishes patient-centred goals;
- Facilitates decision making with patient/family; and
- Recognises and responds to the patient's changing needs.[29]

The mnemonic LIPSERVICE will help ensure that you consider the many aspects of successful communication with patients and patients and will be utilised later in the resource.

L is for Language	• Does your patient speak English? • How well do they speak it? • Do you need to consider getting an interpreter to assist? • What is the person's education level and understanding – will you need to modify the language you use in order to help them understand what you are asking or telling them?
I is for Introduction	• Make sure you introduce yourself to the person, and give them your role – especially if what you do is something that is not commonly known. While most patients will understand the role of a 'doctor', they may not be familiar with what an 'occupational therapist' does. If in doubt, you should explain your role.
P is for Privacy, Dignity and Cultural issues	• Is this a person who is going to be embarrassed by being examined by someone of the opposite gender? • Should you ask before you address them by their first name (many more elderly patients are of a generation who value the respect that being called 'Mr' or 'Mrs' gives them). Be aware of different cultural expectations that you may encounter.

S is for Subjective Questioning	• This is where you take the person's history. • A thorough history will be invaluable in helping to make a diagnosis. • Be aware of the power of 'leading questions' though. • Ask open-ended rather than closed questions to obtain your answers.
E is for Examination	• Some considerations here include talking the person through what it is that you are doing, especially if this is an invasive or unusual procedure for them. • Knowing what is happening and why, as well as what to expect, can help alleviate the person's concern about what it is you are doing to them.
R is for Review	• Talk through what you have done as part of the examination – and what it added to your knowledge of their condition. • For example, 'You were talking about how you get short of breath, and I could hear from listening to your chest that your lungs are quite congested.'
V is for Verdict	• The diagnosis. • What their history and your examination have led you to think is causing their symptoms and signs.
I is for Information	• What does the diagnosis mean for the person? • Having a diagnosis of a lump in the breast can mean many things. • The person needs to know about these.
C is to remind you to Check Understanding	• This is where you determine if what you have said has made sense to the person. • People may only hear the diagnosis and then go into a state of shock – which means they don't process what you tell them next.
E is for End or Exit	• What's going to happen next for the person? • What about follow up? • Referrals to other professionals?

Understanding roles and respecting other professions / role clarification

The need to address complex health and illness problems, in the context of complex care delivery systems and community factors, calls for recognising the limits of professional expertise and the need for cooperation, coordination and collaboration across the professions in order to promote health and treat illness. However, effective coordination and collaboration can occur only when each profession knows and uses the other's expertise and capabilities in a patient-centred way.[30]

The WHO report in 2005 argued that health care providers must work interdependently, demonstrating mutual respect, trust, support and appreciation of each discipline's unique contribution. Although it is changing, the traditional way in which health professional students are educated is uni-professional; and occurs within discipline- and profession-specific groups.[31] Within uni-professional environments students develop a solid grounding in the specific knowledge of their own profession, although many, if not most, students leave educational environments with a cursory understanding of other disciplines' roles and responsibilities.

Interprofessional practice is about developing professionals who are confident in their own core skills and expertise and who are also fully aware and confident in the skills and expertise of fellow health and care professionals.

One educational approach which is thought to assist professionals to develop greater `team awareness' is to understand other professional perspectives through 'shared learning'.[28] Shared learning has the potential to deepen understanding of how professional roles and responsibilities complement each other[30] and engender a greater appreciation of 'common' or overlapping competencies.[32] An enhanced understanding of other professional's roles and responsibilities possible through shared learning can alleviate some of the potential tensions that exist in relation to overlapping competencies between health practitioners.

Interprofessional practice is about developing professionals who are confident in their own core skills and expertise and who are also fully aware and confident in the skills and expertise of fellow health and care professionals.[33]

ACTIVITY THREE

Within your own discipline, how easy/difficult would it be to verbalise your concerns about a colleague's knowledge, skills or competencies?

Thinking outside your own discipline, how would you know what knowledge, skills and competencies other disciplines need/should have? Pick a discipline you have contact with and explain what it is they do, as if you were explaining it to a patient.

Would it be more or less difficult to flag concerns about a colleague from another discipline than your own discipline, and why?

ACTIVITY THREE (continued)

Over your career, how have you learnt about other professional's roles?

Given that optimal interprofessional practice requires you to have a deeper understanding of other professions' roles and responsibilities, identify two professions you would like (or need) to know more about and list strategies you could implement to attain a greater in-depth understanding of that profession's roles and responsibilities.

ACTIVITY THREE: ANSWER AID

Each profession's roles and responsibilities vary within legal boundaries; actual roles and responsibilities change depending on the specific care situation. Professionals may find it challenging to communicate their own role and responsibilities to others. For example, Lamb et al.[34] discovered that staff nurses had no language to describe the key care coordination activities they performed in hospitals. Being able to explain what other professionals' roles and responsibilities are and how they complement one's own is more difficult when individual roles cannot be clearly articulated. Safe and effective care demands crisply defined roles and responsibilities.

Specific Roles/Responsibilities Competencies:

RR1. Communicate one's roles and responsibilities clearly to patients, families, and other professionals.

RR2. Recognise one's limitations in skills, knowledge, and abilities.

RR3. Engage diverse health care professionals who complement one's own professional expertise, as well as associated resources, to develop strategies to meet specific patient care needs.

RR4. Explain the roles and responsibilities of other care providers and how the team works together to provide care.

RR5. Use the full scope of knowledge, skills, and abilities of available health professionals and health care workers to provide care that is safe, timely, efficient, effective, and equitable.

ACTIVITY THREE: ANSWER AID (continued)

RR6. Communicate with team members to clarify each member's responsibility in executing components of a treatment plan or public health intervention.

RR7. Forge interdependent relationships with other professions to improve care and advance learning.

RR8. Engage in continuous professional and interprofessional development to enhance team performance.

RR9. Use unique and complementary abilities of all members of the team to optimise patient care.

(Interprofessional Education Collaborative, 2011)[17]

Reflection

The importance of personal reflection in interprofessional practice was highlighted in a national study designed to inform the further development of IPL in Australian health professional education and workforce development. The report identified the importance of reflection as interprofessional education centred on:

> …the relational aspects of practice or practising, with a learning and reflective focus on the team, as well as the individual, and is responsive to a body of knowledge and ethical orientation that engages with teams and team functioning as well as individuals and individual functioning.[5]

Processes that facilitate both individual and team reflection are critical to increase awareness and understanding of intra and inter personal relationships. One such tool to assist in the process of personal or team-based reflection to generate well-considered steps to problem-solving with team members, patients and clients, is the mnemonic ASPIRIN.

A	Acknowledge the problem	Basically, is there something that needs to be addressed?
S	Situational analysis	What is the cause of the situation? How did it come about and who is involved? What is likely to happen if you don't act? What are the risks if you do act?
P	Provide some solutions.	There is almost always more than one approach that could be used to try and solve this situation. Decide on which is the most suitable.
I	Implement	Your preferred solution.
R	Review the outcome	How did it help? Do you need to try something else?
I	Inform stakeholders	Let people know – communication is very important.
N	Next steps	Is this a temporary fix? Do you need to look at a different long term solution? Will the problem occur again and again unless steps are taken to resolve it in the longer term?

ACTIVITY FOUR

Consider a problem (past or present) and utilise ASPIRIN to assist you to generate new ways of thinking about that situation.

Reflect on how you consider interprofessional practice has the potential to impact upon patient outcomes.

Reflect on what you have covered in this resource thus far and consider what changes you need to make to ensure your own practice is interprofessionally-focussed.

Interprofessional practice (IPP) in community-based dementia care

What is dementia?

- Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.[35,36]
- At present there are over 321,600 Australians living with dementia and this number is expected to increase by one-third to 400,000 in less than ten years.[37]
- Without a medical breakthrough, the number of people with dementia is expected to be almost 900,000 by 2050.[37]
- An estimated 1.2 million Australians are caring for someone with dementia and it is the third leading cause of death in Australia.[37]
- Most diseases causing dementia are at present incurable, for example Alzheimer's disease, vascular (multi-infarct) disease and Lewy body disease (LBD).
- Currently, an estimated 60% to 75% of diagnosed dementias are of the Alzheimer's and mixed (Alzheimer's and vascular dementia) type.[36]

Models of dementia care

- Up until the 1950s, dementia was regarded as a form of insanity that required segregation from society by way of detention in workhouses, institutions or asylums.[36,38]
- The decline of the asylum system has seen the prevention of admissions through the provision of community facilities, discharging of institutionalised patients and the establishment of community support programs.[36]
- Until recent times, it was widely believed that persons with Alzheimer's and other dementias had no insight into their condition and that their subjective experience was of little importance. While those caring for patients with dementias were encouraged to treat them with dignity and respect, the focus of care was on meeting the basic physical requirements of feeding, bathing and dressing, and controlling symptoms and behaviours pharmaceutically.[36]

- Those working in mental health and aged care were ‘largely seen as incapable of working in the more demanding areas...Those considered dynamic and ambitious were rarely found in the milieu of dementia care’.[36]
- In the 1990s, Professor Thomas Kitwood proposed a new model of person-centred care that acknowledges the many factors that influence an individual with dementia.[39]
- The gradual shift towards a person-centred approach to care has resulted in nearly two-thirds of people with dementia living at home.[40,41]
- People with dementia living at home alone are 20 times more likely to move into residential or nursing care than those living with a family member.[40]
- Carers of people with dementia have higher levels of stress and distress than other caring populations. Stressed and distressed carers have higher mortality and morbidity than non-carers, and carer distress is one of the predictors of institutionalization of the person with dementia.[40]

Community-based care

- Community dementia care is growing due to a combination of patient choice to remain in their home and the relative savings in costs compared with residential care.[42]
- Within primary care, interprofessional teamwork is essential to develop an integrated approach to promoting and maintaining the health of the population whilst improving service effectiveness.[43]

A more complete literature review about interprofessional practice in community-based dementia care is available in Section Four.

Resource activities in relation to interprofessional practice (IPP) in community-based dementia care follow in Section Three.

The scenario in Section Three highlights the importance of interprofessional practice (IPP) in community-based dementia care and its implications for interprofessional collaborative practice.

Section Three: Scenario – Husband and wife are not coping

Scenario

Mr Jones is seeing his general practitioner (GP) about his medication. It has been a difficult interview as Mr Jones is reluctant to give the GP information about either himself or his wife. The GP is concerned that Mr and Mrs Jones may not be coping. The geriatrician and social worker conduct a home visit to the Jones' to assess what care they might need.

List of characters

- GP
- Mr Bob Jones
- Social worker
- Senior geriatrician
- Registered nurse
- Mrs Jones
- Medical secretary

What to do next

Section Three of the resource requires that you:

1. Watch each scene of the associated resource 'Husband and wife are not coping':
    - Scene One – GP clinic
    - Scene Two – ACAT office/Mr Jones' home
    - Scene Three – Car park/GP office/ACAT office
    - Scene Four – Outside the Jones' house
    - Scene Five – The Jones' lounge room
    - Scene Six – ACAT office
2. After you have watched a scene, complete the activity questions relevant to that scene.
3. If necessary, refer to the 'answer aid' text box positioned after the activity questions for hints relating to interprofessional practice (IPP) in community-based dementia care.

Scene One: GP Clinic

Please watch ‘Husband and wife are not coping’: Scene One

Notes:

ACTIVITY FIVE

The GP is concerned about Mr and Mrs Jones. What are the GP's options at this point?

Which health professionals do you think make up the Aged Care Assessment Team (ACAT)? What do you know about the role of the health professions you have identified?

ACTIVITY FIVE (continued)

What reasons might there be for Mr Jones' reluctance to provide information to the GP?

What communication strategies could the GP use to elicit more information?

ACTIVITY FIVE: ANSWER AID

The GP is concerned about Mr and Mrs Jones. What are the GP's options at this point?

1) The GP could make a referral to the local Aged Care Assessment Team, explaining to Mr and Mrs Jones the services of ACATs. ACATs provide information on suitable care options and can help arrange access or referral to appropriate residential or community care services such as Home and Community Care (HACC). An ACAT assessment and approval is required before people can access residential aged care, Community Aged Care Packages (CACPs) or Extended Aged Care at Home (EACH) Packages.

2) Make another appointment for Mr and Mrs Jones together to see Mrs Jones in person, monitor their progress and discuss an ACATs referral. Other family members could also be included.

Which health professionals do you think make up the Aged Care Assessment Team (ACAT)? What do you know about the role of the health professions you have identified?

ACATS are usually based in hospitals or community centres and may include a doctor, nurse, social worker, physiotherapist or occupational therapist.

Doctors – apply the principles and procedures of medicine to prevent, diagnose, care for and treat patients with illness, disease and injury and to maintain physical and mental health. They identify and advise on appropriate treatment options or preventive measures.[44]

ACTIVITY FIVE: ANSWER AID (continued)

Nurses are capable of assessing, planning, implementing, and evaluating care independently of physicians, and they provide support from basic triage to emergency surgery.[45]

Social workers engage with people of any age to achieve the best possible levels of personal and social wellbeing. Social workers can undertake comprehensive psychosocial assessments with patients. They then assist patients to regain or achieve their desired outcomes through evidence-based interventions and strategies.[46]

Physiotherapists support patients across the lifespan to maximise their mobility and functional capacities, and thereby improve their independence and general wellbeing. Physiotherapists assist patients with musculoskeletal, cardiothoracic and neurological problems, and can also provide advice on lifestyle modification, chronic disease self-management and health promotion/prevention activities.[46]

Occupational therapists (OTs) assist people across the life span to overcome limitations caused by injury or illness, psychological or emotional difficulties, developmental delay or the effects of aging. They assist people to move from dependence to independence, maximising personal capability.[46]

What reasons might there be for Mr Jones' reluctance to provide information to the GP?

Carers of people with dementia often have higher levels of stress and distress than other caring populations. His mood may be flat or irritable in general which is impacting on his communication.

ACTIVITY FIVE: ANSWER AID (continued)

Some of the reasons for Mr Jones' reluctance might include:

- Anxious about why the GP wants to know the information or what he may do with it, and consequently does not want to reveal how Mrs Jones' health has declined;
- Fears judgment or feelings of failure, and feels embarrassed he is not coping;
- Doesn't want his wife cared for both anyone but himself and fears he will be separated from his wife if her health declines;
- Fears an ACAT assessment may lead to recommendations that Mrs Jones needs to move into a nursing home, and perceptions about nursing homes may lead him to not disclose how difficult it is at home; and
- May not understand what dementia is and his wife's prognosis.

What communication strategies could the GP use to elicit more information?

The GP could employ good overall communication skills to put Mr Jones more at ease and create an environment in which he feels more comfortable. Good communication skills include establishing and maintaining eye contact, appropriate body language such as an open posture, active listening such as nodding or making noises of agreement, and encouragement to indicate understanding.

ACTIVITY FIVE: ANSWER AID (continued)

Other steps the GP could take include:

- Explaining clearly upfront why she has to ask so many questions, and giving more detail about the range of services that may be able to assist them to stay at home;
- Acknowledging that it must be hard caring for another person and the number of years they have been together and asking what is worrying Mr Jones the most about the future. This would assist in normalising Mr Jones' feelings;
- Using positive language, e.g. "As things change, we can work on the options and come up with a plan together";
- Determining goals of care and identifying any specific desires for how information should be shared with family members; and
- Offering additional information (patient resources, information sheets, referrals etc.).

Scene Two: ACAT office/Mr Jones' home

Please watch 'Husband and wife are not coping': Scene Two

Notes:

ACTIVITY SIX

Should the GP's referral letter mention that Mr and Mrs Jones have not consented to the ACAT referral? Do you think the GP is justified in contacting the ACAT without Mr Jones' consent?

How can we address these types of communication issues with patients and carers?

How might the registered nurse follow up with the social worker to discuss his understanding of the role of the team and the organisation in such cases?

ACTIVITY SIX: ANSWER AID

Should the GP's referral letter mention that Mr and Mrs Jones have not consented to the ACAT referral? Do you think the GP is justified in contacting the ACAT without Mr Jones' consent?

The GP should work from the ethical principal of *beneficence* (a practitioner should act in the best interest of the patient). Consequently, the letter should indicate that Mrs Jones appears not to be competent or capable of making an autonomous decision as she is cognitively impacted by her dementia and not able to understand the potential consequences of the referral. Mr Jones, however, could provide consent; the letter needs to make clear if he has or has not provided consent.

See 'Interprofessional Learning in Simulation Project: It's just a fracture! – Acute episode with underlying chronic conditions and social considerations Facilitators' Guide' for more detailed information on the concepts of beneficence, non-maleficence and duty of care.

How can we address these types of communication issues with patients and carers?

Being mindful and respectful in communications with patients is demonstrating the principles of autonomy, beneficence, non-maleficence and duty of care. Communication issues can be addressed by:

- Identifying the factors that patients, carers and families are fearful of and what the barriers are to engaging with other services;

ACTIVITY SIX: ANSWER AID (continued)

- Informing patients that there are services that could be accessed and that it can be helpful to meet the teams involved in delivering those services to understand what assistance can be provided; and
- Reassuring patients, carers and/or families that a referral to a service does not necessarily mean the service has to be used.

How might the registered nurse follow-up with the social worker to discuss his understanding of the role of the team and the organisation in such cases?

Effective coordination and collaboration can occur only when each profession knows and uses the other's expertise and capabilities in a patient-centred way.[30] Approaches might include:

- Directly speaking to the social worker via telephone or organising a face to face appointment;
- Asking the social worker to discuss team members, their roles and responsibilities and the role of the organisation; and
- Discussing what care has been delivered and how best that care could be provided by both services in the future, if they are both involved.

Adhering to the five standards of effective communication[47] in health care is likely to facilitate improvements in the exchange of information between health care professionals.

ACTIVITY SIX: ANSWER AID (continued)

Information should be[48]:

- Complete – It answers all questions asked to a level that is satisfactory to those involved in the exchange of information;
- Concise – Wordy expressions are shortened or omitted. It includes only relevant statements and avoids unnecessary repetition;
- Concrete – The words used mean what they say; they are specific and considered. Accurate facts or figures are given;
- Clear – Short, familiar, conversational words are used to construct effective and understandable repetition; and
- Accurate – The level of language is apt for the occasion; ambiguous jargon is avoided, as are discriminatory or patronising expressions.[47]

Scene Three: Car park/GP office/ACAT office

Please watch ‘Husband and wife are not coping’: Scene Three

Notes:

ACTIVITY SEVEN

Disparate health care record-keeping contributes to miscommunication in health care delivery. What approaches could you suggest to improve this problem?

Are you aware of any initiatives in record-keeping systems that will facilitate more efficient communication across health care providers?

Think about a situation you have experienced with a patient where another health discipline was involved in care delivery. Consider what difficulties that discipline may have encountered and how you may have been able to assist in alleviating those difficulties.

ACTIVITY SEVEN: ANSWER AID

Disparate health care record-keeping contributes to miscommunication in health care delivery. What approaches could you suggest to improve this problem?

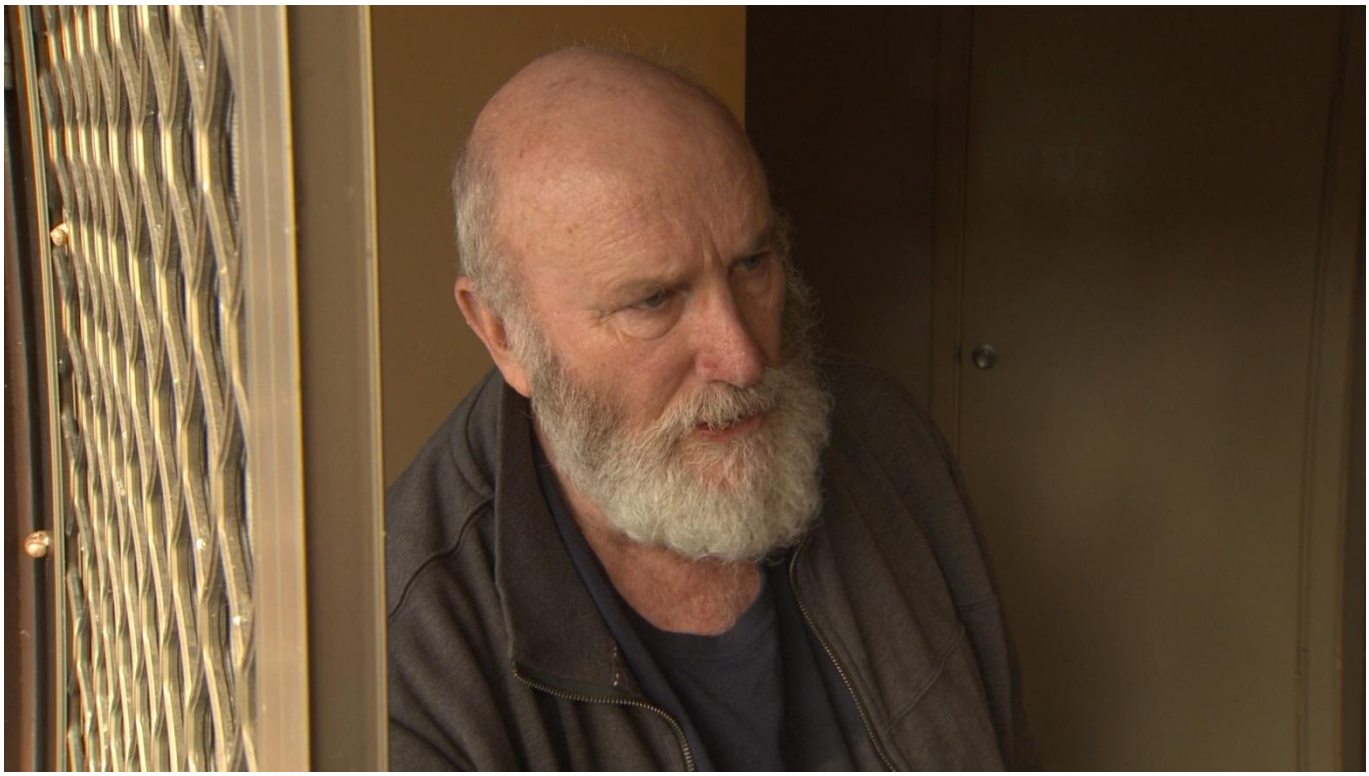
- Having standard assessment forms and discharge forms;
- Ensuring that all parties (patient and service providers involved in care) have been provided with discharge documents;
- Ensuring notes are completed after every occasion of service; and
- Ensuring discharge planning documentation is complete.

Are you aware of any initiatives in record-keeping systems that will facilitate more efficient communication across health care providers?

The Medicare eHealth record is a secure online summary of a patient's key health information, which means both the patient and the health care organisations they authorise can quickly access information regarding their health: http://www.humanservices.gov.au/customer/news/take-control-of-your-health-and-register-for-an-ehealth-record-today

Scene Four: Outside the Jones' house

Please watch 'Husband and wife are not coping': Scene Four



Notes:

ACTIVITY EIGHT

How would you describe a social worker's role in the health care team?

What can be done to address Mr Jones' anxiety?

ACTIVITY EIGHT: ANSWER AID

How would you describe a social worker's role in the health care team?

A social worker works with people who have been socially excluded or who are experiencing crisis. Their role is to provide support to enable service users to help themselves. They maintain professional relationships with service users, acting as guides, advocates or critical friends.

Social workers work in a variety of settings within a framework of relevant legislation and procedures, supporting individuals, families and groups within the community. Settings may include the service user's home or schools, hospitals or the premises of other public sector and voluntary organisations.

What can be done to address Mr Jones' anxiety?

Steps the health care team could take include:

- Offering appropriate explanations at the beginning of each visit;
- Succinctly explaining why they are there;
- Scheduling consultations and visits from health care professionals Mr and Mrs Jones have met previously;
- Identifying and validating what Mr Jones' concerns, and acknowledging his efforts;
- Clarifying Mr Jones' understanding of the team and the process; and
- Explaining the importance of autonomy in health settings.

Scene Five: The Jones' lounge room

Please watch 'Husband and wife are not coping': Scene Five

Notes:

ACTIVITY NINE

Who is responsible for ensuring that medications are taken as prescribed? Who is monitoring the prescriptions?

What is the role of a pharmacist in this situation?

What strategies could the geriatrician use to try to connect with Mr Jones?

ACTIVITY NINE: ANSWER AID

Who is responsible for ensuring that medications are taken as prescribed? Who is monitoring the prescriptions? What is the role of a pharmacist in this situation?

The team involved in Mrs Jones' care is responsible for ensuring her medications are taken as prescribed. This involves Mr Jones, the GP (explaining how and when to take the medications and any potential side-effects), and the pharmacist dispensing the medication.

A community pharmacist is responsible for controlling, dispensing and distributing medicine. They work to legal and ethical guidelines to ensure the correct and safe supply of medical products to the general public. They are involved in maintaining and improving people's health by providing advice and information as well as supplying prescription medicines.

The role includes[49]:

- Providing knowledge of the medications and what they do to assist;
- Providing knowledge and ideas on ways of facilitating adherence;
- Preparing dosette boxes and Webster packs, usually for the elderly but also for those with memory/learning difficulties, where tablets are placed in compartments for specified days of the week;
- Providing a prescription intervention service; and
- Arranging the delivery of prescription medicines to patients.

At the time of dispensing, the pharmacist should have discussions with Mr Jones (repeated, if necessary) about how and when each medication should be administered, as adherence issues may facilitate reducing the barriers.

Scene Six: ACAT office

Please watch ‘Husband and wife are not coping’: Scene Six

Notes:

ACTIVITY TEN

How has the geriatrician helped bring the social worker on board?

What can the geriatrician say to the daughter about her parents? Does he need permission? How should this be handled?

How has this discussion promoted person-centred care (PCC)?

ACTIVITY TEN: ANSWER AID

How has the geriatrician helped bring the social worker on board?

The geriatrician has engaged the social worker by:

- Helping the social worker understand that Mr Jones irritability may result in Mr Jones declining help that is required;
- Assisting him to understand that permission needs to be gained otherwise patients, carers and family members can become irritated; and
- Reinforcing the need to be respectful and mindful of the manner in which the health care team communicates with Mr Jones to ensure that they are compassionate and respectful and avoid being judgmental.

What can the geriatrician say to the daughter about her parents? Does he need permission? How should this be handled?

The concept of beneficence – a practitioner should act in the best interest of the patient – and non-maleficence – "first, do no harm" – are important points to consider when engaging family members and/or carers when consent has not been provided. Ethical dilemmas can arise in health care when what is in the patient's best interests conflicts with their customs, values and spiritual beliefs, or those of their carer/guardian. In a health care context, paternalism has come to mean behaving in a way that does not respect a person's autonomy, for that person's supposed good. This may result in a conflict between the ethical principles of autonomy and beneficence (or 'to do good').

ACTIVITY TEN: ANSWER AID (continued)

The principle of non-maleficence can be summarised as an obligation to 'above all, do no harm' and has been described as the cornerstone of health care on which practices and legislation relating to duty of care, negligence and malpractice are based.

In this scenario, there is an ethical conflict for the ACAT between the obligation to prevent harm (i.e. duty of care to Mrs Jones) and the right for Mr Jones to make autonomous decisions about his wife's care. Mrs Jones is not competent, or capable of autonomous decision-making, as she is cognitively impaired by her dementia. As her carer/guardian, Mr Jones appears competent, but his actions (or inactions) may be placing Mrs Jones at risk of harm. Mr Jones' autonomy may also be violated if the ACAT contact his daughter without his consent.

For more information on beneficence and non-maleficence, see the discussion in 'Section Four: Literature Review – Duty of Care' in Interprofessional Learning in Simulation Project: It's just a fracture! – Acute episode with underlying chronic conditions and social considerations.

ACTIVITY ELEVEN

Watch Scenes One to Six again and complete LIPSERVICE (below) to determine how focussed the individual characters were on the needs of service users and carers.

First letter	LIPSERVICE Questions	Your notes
L is for Language	• Does your patient speak English? • How well do they speak it? • Do you need to consider getting an interpreter to assist? • What is the person's education level and understanding – will you need to modify the language you use in order to help them understand what you are asking or telling them?	
I is for Introduction	• Make sure you introduce yourself to the person, and give them your role – especially if what you do is something that is not commonly known. While most patients will understand the role of a 'doctor', they may not be familiar with what an 'occupational therapist' does. If in doubt, you should explain your role.	
P is for Privacy, Dignity and Cultural issues	• Is this a person who is going to be embarrassed by being examined by someone of the opposite gender? • Should you ask before you address them by their first name (many more elderly patients are of a generation who value the respect that being called 'Mr' or 'Mrs' gives them). • Be aware of different cultural expectations that you may encounter.	
S is for Subjective Questioning	• This is where you take the person's history. • A thorough history will be invaluable in helping to make a diagnosis. • Be aware of the power of 'leading questions' though. • Ask open-ended rather than closed questions to obtain your answers.	

E is for Examination	• Some considerations here include talking the person through what it is that you are doing, especially if this is an invasive or unusual procedure for them. • Knowing what is happening and why, as well as what to expect, can help alleviate the person's concern about what it is you are doing to them.
R is for Review	• Talk through what you have done as part of the examination – and what it added to your knowledge of their condition. • For example, 'You were talking about how you get short of breath, and I could hear from listening to your chest that your lungs are quite congested.'
V is for Verdict	• The diagnosis. • What their history and your examination have led you to think is causing their symptoms and signs.
I is for Information	• What does the diagnosis mean for the person? • Having a diagnosis of a lump in the breast can mean many things. • The person needs to know about these.
C is to remind you to Check Understanding	• This is where you determine if what you have said has made sense to the person. • People may only hear the diagnosis and then go into a state of shock – which means they don't process what you tell them next.
E is for End or Exit	• What's going to happen next for the person? • What about follow up? • Referrals to other professionals?

Section Four: Literature review – Interprofessional practice (IPP) in community-based dementia care

What is dementia?

The World Health Organization (WHO),[35] cited by Biernacki,[36] defines dementia as:

> A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

'The process of dementia is that it is a progressive syndrome; symptoms become more marked and impact more and more on the individual's life, eventually pervading all areas'.[36]

At present there are over 321,600 Australians living with dementia and this number is expected to increase by one-third to 400,000 in less than ten years. Without a medical breakthrough, the number of people with dementia is expected to be almost 900,000 by 2050. There are approximately 24,400 people in Australia with Younger Onset Dementia (a diagnosis of dementia under the age of 65, including people as young as 30) and one in four people over the age of 85 have dementia. An estimated 1.2 million Australians are caring for someone with dementia and it is the third leading cause of death in Australia.[37]

Most diseases causing dementia are at present incurable, for example Alzheimer's disease, vascular (multi-infarct) disease and Lewy body disease (LBD). Currently, an estimated 60% to 75% of diagnosed dementias are of the Alzheimer's and mixed (Alzheimer's and vascular dementia) type, 10% to 15% are Lewy body type, with the remaining types representing an entire spectrum of dementias, including fronto temporal lobar degeneration (FTLD), alcoholic dementia (Korsakoff's syndrome), pure vascular dementia, Huntington's disease, Parkinson's disease and Cruetzfeldt-Jakob disease (CJD).[36]

The most common forms of dementia

Alzheimer's disease

Alzheimer's disease is a progressive, degenerative illness that attacks the brain. As brain cells shrink or disappear abnormal material builds up as 'tangles' in the centre of the brain cells and 'plaques' outside the brain cells. These disrupt messages within the brain, damaging connections between brain cells. The brain cells eventually die and this means that information cannot be recalled or assimilated. As Alzheimer's disease affects each area of the brain, certain functions or abilities are lost.[50]

Why these changes happen and why some people but not others develop Alzheimer's disease is not yet understood. It is thought that a combination of genetic propensity and biochemical, environmental and immune processes, all of which are being investigated, may prove to have a part to play. A very small number of people will inherit Alzheimer's disease genetically.[36]

Vascular dementia

Vascular dementia accounts for approximately 20%-25% of all dementias. Dementia associated with cerebrovascular disease is caused by multiple infarctions throughout the brain. This means that blood supply to parts of the brain is restricted or blocked and the brain is deprived of oxygen, causing cells in the brain to die. Vascular dementia is closely associated with hypertension and other contributing factors include diabetes mellitus and smoking.[36,51]

The risk factors for vascular dementia are similar to those for stroke and other cardiovascular diseases. Risk factors may be associated with lifestyle choices, e.g. poor diet, smoking and lack of exercise, and can therefore be minimised in many cases. Furthermore, the choice of healthier lifestyle options by someone with existing vascular dementia may reduce the risk of progression of dementia.[36,51]

Lewy body disease (LBD)

Dementia with Lewy bodies is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells.[50]

LBD is characterised by fluctuating levels of alertness and cognition, hallucinations (most commonly visual), Parkinson's symptoms (such as shuffling gait and falls) and the presence of

dementia symptoms. The causes of LBD are not well understood and it is not thought to be a strongly hereditary disease.[36]

Fronto temporal lobar degeneration (FTLD)

Fronto temporal dementia is the second most common cause of Younger Onset Dementia and onset is generally between the ages of 40 and 65. FTLD is the name given to dementias that result from degeneration to one or both frontal or temporal lobes of the brain. There is a significant genetic component to FTLD and around 50% of those diagnosed have a family history.

> Personality, behaviour and reasoning are among the elements controlled by the brain's frontal lobes. Where a disease process or injury damages this area of the brain dramatic change in social behaviour and loss of personal awareness are evident... Typically in the early stages memory is not impaired.[36,50]

Other types of dementias

Huntington's disease

Huntington's is a rare, hereditary disease characterised by chronic, progressive, involuntary movement of the limbs and facial muscles, psychological changes and dementia. Symptoms do not usually develop until after 30 years of age.[50,51]

Parkinson's disease

Parkinson's disease is a degenerative disorder of the central nervous system. The most obvious symptoms are movement-related; these include shaking, rigidity, slowness of movement and difficulty with walking and gait. As the disease progresses, cognitive and behavioural problems may arise, with dementia commonly occurring in the advanced stages of the disease.[50,51]

Korsakoff's syndrome

Korsakoff's syndrome is a neurological disorder caused by a lack of thiamine (vitamin B_1) in the brain. Its onset is linked to chronic alcohol abuse and/or severe malnutrition. The syndrome involves severe impairment of recent memory.[51]

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob's disease is a rare, transmissible form of dementia. In CJD, the brain tissue develops holes and takes on a sponge-like texture. This is due to a type of infectious protein called a prion.[51]

Other conditions that may produce or be associated with dementia include:

- HIV/AIDS;
- Multiple sclerosis;
- Head injuries;
- Brain tumours and haemorrhages;
- Brain infections;
- Exposure to certain toxins; and
- Substance abuse.[50]

A medical diagnosis at an early stage is important and will exclude any reversible conditions. A correct diagnosis of the type of dementia is vital as treatments, including medications, may vary considerably depending on the underlying pathology.

Table 1: Stages of dementia

Early stage dementia		
Cognitive symptoms	**Behaviour**	**Emotional response**
Mild impairment of short-term memory Difficulty with language and reading Difficulty making decisions Difficulty concentrating Difficulty making judgments Hallucinations (rare)	Forgetting birthdays, anniversaries, appointments Losing things Getting lost while driving Forgetting peoples' names Looking to others to confirm correctness of words or actions or conversely rejecting assistance offered Confabulating – making up information in the absence of the ability to recall correct information	Worry Social embarrassment Fear of going mad Suspicion Anxiety Denial Frustration Irritability Depression Tearfulness Unconcern
Middle stage dementia		
Cognitive symptoms	**Behaviour**	**Emotional response**
Loss of short-term memory Patchy long-term recall Dysphasia Difficulty planning, sequencing and using judgment Disorientation to time, place or person	Unable to pursue hobbies Unable to drive safely Misidentifying family members Loss of friendships and social contacts Disturbed sleep Difficulty with daily activities – washing, dressing, preparing food, shopping Walking and getting lost Self-harm attempt (rare)	Withdrawal Depression Paranoia Agitation/anxiety Apathy Anger Frustration Incongruence/lability Aggression Bereavement reaction Acceptance Tearfulness Unconcern

Table 1: Stages of dementia (continued)

Late stage dementia		
Cognitive symptoms	**Behaviour**	**Emotional response**
Loss of short and long-term memory Loss of judgment, planning and sequencing skills Severe dysphasia and aphasia Dysphagia Loss of ability to respond to own needs or express needs in easily understood ways	Unable to anticipate or meet daily needs – washing, dressing Incontinence Constant walking Difficulty with eating, drinking and self-feeding Social withdrawal Rejection of assistance – violence Repetitive actions and words/sounds	Placidity Agitation Anger Aggression Anxiety and panic Depression Complete withdrawal from interaction with others

Source: Biernacki, 2007[36]

Models of dementia care

Up until the 1950s, dementia was regarded as a form of insanity that required segregation from society by way of detention in workhouses, institutions or asylums. In fact, 'The Oxford English Dictionary at the end of the eighteenth century defines dementia as coming from the Latin *demens* and meaning "senseless, mad, foolish"'. Thornicroft and Tansella,[38] cited by Biernacki,[36] identified three distinct periods in the development of mental health care:

1. The rise of the asylum period between 1880 and 1950;
2. The decline of the asylum beginning in the 1950s; and
3. Balanced care, which is currently underway.

Rollin,[52] cited by Biernacki,[36] asserts that asylums were in effect society's dustbins where, as well as genuine patients, staff had to deal with:

> An assorted ragbag of social misfits: people with varying grades of learning disability; those addicted to drugs and alcohol, either acutely or chronically disturbed; those with personality disorders of protean varieties; vagrants; the aged who had become an embarrassment to their kin; pregnant single women who had been cast out by their

> relatives; and anyone who by hook – and not infrequently by crook – could be squeezed into whatever the law required to be certified.

The decline of the asylum system has seen the prevention of admissions through the provision of community facilities, discharging of institutionalised patients and the establishment of community support programs. In the last 50 years there has been an increase in the acceptance of psychological therapies in mental health care, yet therapies for older people and particularly those with dementia have been slower to develop. The reasons for this include ageism, the low status afforded those who work in aged care and the belief that older adults are untreatable.[36]

In the 1960s and 1970s, treatments for people with dementia began to emerge. Reality orientation (RO) was claimed as a major advancement in the care of people with dementia and is still in use today. 'RO techniques are based on repetitive presentation of information regarding time, place and person' and is 'aimed at improving orientation, avoiding under-stimulation and sustaining interaction with others. This, it was felt, would improve self-esteem and reduce the risk of problem behaviour developing.' In the 1980s another technique was developed by Feil[53] called validation therapy. Validation therapy is 'a humanistic approach based on accepting another's reality and experience rather than insisting they accept ours.' Feil's method was the beginning of person-centred dementia care.[36]

The philosophy of person-centred care (PCC) was described by Professor Thomas Kitwood[39] in his seminal work *Dementia Reconsidered*. In the early twentieth century, Alzheimer's and other dementias were identified as diseases and mental illnesses:

> From this point the search was on to describe the pathology of the disease, and all the other identified dementias, in order to understand how the disease progressed and how symptoms could be controlled, eliminated and the disease itself cured. In the hunt it turned out the person with the dementia, the individual as distinct from the signs and symptoms they displayed, was the last to be considered or consulted.[36]

Until recent times, it was widely believed that persons with Alzheimer's and other dementias had no insight into their condition and that their subjective experience was of little importance. While those caring for patients with dementias were encouraged to treat them with dignity and respect, the focus of care was on meeting the basic physical requirements of feeding, bathing and dressing, and controlling symptoms and behaviours pharmaceutically. Furthermore, those working in mental health and aged care were 'largely seen as incapable of working in the more

demanding areas...Those considered dynamic and ambitious were rarely found in the milieu of dementia care'.[36]

In the 1990s, Professor Kitwood proposed a new model of person-centred care that acknowledges the many factors that influence an individual with dementia. The following equation was used to summarise these influences:

$$D = P + B + H + NI + SP$$

> In the person-centred model of dementia care D, or dementia, is seen as the sum of the individual's Personality, Biography or life story, their physical Health, Neurological Impairment, and Social Psychology, the social and physical context within which the individual lives. It is these factors that determine the pattern of a person's experience with dementia and how this is expressed.[36,39]

The basis of person-centred care is understanding the importance of supporting an individual's personhood, and recognising and responding to each person as a human being, with a unique identity and worthy of respect.

Similarly, Booker[54] describes person-centred care as encompassing four major elements:

- **V** – A value base that asserts the absolute value of all human lives regardless of age or cognitive ability;
- **I** – An individualised approach, recognising uniqueness;
- **P** – Understanding the world from the perspective of the service user; and
- **S** – Providing a social environment that supports psychological needs.

Kitwood also believed that:

> The psychosocial environment that has been created to care for people with dementia by the process of dehumanising the individual and relating to the individual in a way that detracts from their personhood has the consequence of exacerbating the dementing process.[39]

In other words, the traditional approach to dementia care makes dementia worse. Many of the interactions those working in dementia care have with patients is unintentionally malignant or abusive and serves to disempower, patronise, mock or disturb those in their care. Kitwood termed these interactions Malignant Social Psychology (MSP).[36,39]

Booker cites Kitwood's observations of MSP and suggests:

> The root of MSP lies within our societal values. People with dementia are not valued in a society where youth and intellectual prowess receive the highest accolades. At best, people with dementia are ignored by society. At worst, they are discriminated against. This is society's response to people with dementia generally, and it has all too often become the professional caring response. In care settings, this lack of value manifests itself as MSP.[54]

Kitwood's philosophy of person-centred care advocates practices based on supporting personhood and meeting psychological needs, which then leads to an improvement in the quality of life and wellbeing of persons with dementia and the potential to reverse the progress of the disease in some individuals. 'In the long term many of the very negative endstage symptoms previously thought to be a consequence of the dementia will prove to have been consequences of the negative nature of care practices'.[36]

The gradual shift towards a person-centred approach to care has resulted in nearly two-thirds of people with dementia living at home. In many countries, an overriding objective for social care is to maintain people with dementia in their own home for as long as possible. Post diagnosis, '...the person with dementia will need emotional support and increasing assistance with activities of daily living'. The increased care needs of the person with dementia affect family/carers' lives whether cohabitating or living nearby.[40,41]

> People with dementia living at home alone are 20 times more likely to move into residential or nursing care than those living with a family member...The proportion of people living in care homes rises with age, from 27% for those aged between 65 and 74, to 61% for those aged over 90. This demographic is most likely due to spouses being less willing to use care homes for their partners than are adult children for parents.[40]

Iliffe and Drennan[41] identified four possible hazards of the primary care model for people with dementia:

1. Referral – which can be a desirable route to accurate diagnosis and specialist care, can sometimes be a form of disposal of the patient;
2. Clinical management – 'Management' of dementia as a clinical problem places great emphasis on the skills and resources of the managers, but little on the patients and their social support, who become the objects of interventions and the recipients of services;

3. Underutilisation of resources – resources may be underutilised in some instances (for example, day care respite), with money sitting under one budget heading being underspent because of cash limits in another; and
4. Information – Patients, carers, health care professionals and service planners all need information, but it may be unclear who is responsible for collecting, analysing and disseminating the required information.

Downs and Bowers[40] identify seven domains of need for the community-dwelling person with dementia:

- Health and mobility;
- Self-care and toileting;
- Social interaction;
- Thinking and memory;
- Behaviour and mental state;
- House care; and
- Community living.

The individual's needs vary, depending on whether or not they live alone. The tension between personhood and safety means 'Maintaining the person in their own home requires a balance between minimising risk and maximising independence'.[40]

Support for carers should also be considered:

> Carers of people with dementia have higher levels of stress and distress than other caring populations. Stressed and distressed carers have higher mortality and morbidity than non-carers, and carer distress is one of the predictors of institutionalization of the person with dementia.[40]

The pattern of associations between care-related stressors and outcomes are different for spouses and adult children. This is probably due to the fact that spouses are usually themselves aging and are more likely to be cohabitating with the person with dementia. Adult children are more likely to be living apart and often have their own lives and interests to serve as diversions from their role as carers.[40]

Aneshensel et al.[55] emphasised the importance of changing needs over time when determining support:

> The form, context and timing of intervention should depend to a considerable extent on where caregivers are in their careers (as carers), and involve an understanding of what has passed before and what is likely to lie ahead. That is, the problems encountered yesterday should be viewed against the backdrop of yesterday with an eye towards tomorrow.

Research suggests that 'support of both carers and people with dementia contributes to personal wellbeing and the ability to continue care, and that the most effective interventions take both into consideration'.[40]

Interprofessional practice (IPP) in community-based care

Tataw[56] identifies abilities that provide a supportive environment for interprofessional practice to take place, therefore optimising access and utilisation of community resources:

- To provide altruistic leadership that promotes collaborative models of service delivery centred on service beneficiaries and involves all health and social care stakeholders;
- Create a community culture of respect, sensitivity to professional differences and collaborative decision-making driven by the needs of community members;
- Collaboratively develop organisational or community health goals focussed on the needs of community members;
- Ensure service coordination across health settings, organisations, and domains;
- Ensure organisational and individual professional incentives-based participatory behaviour and teamwork; and
- Create an infrastructure for collective community response to the health needs of community members.

Table 2: Comparison of individual, organisational and community dimensions of interprofessional practice

Change variables	Individual practice	Community and organisational practice
Leadership	Collaborative, team, interprofessional leadership	Altruistic leadership that supports collaborative service delivery
Culture	Team and collaborative	Culture of respect, sensitivity and collaborative decision-making
Organisational environment	Supportive of team and collaborative practice	Organisational infrastructure for collaborative response to community health needs
Skills, knowledge, abilities	Well-developed team skills, knowledge, and abilities	N/A
Structure	Interdependent teams and collaborative structures within Organizations, across Organizations and across domains	Infrastructures that support service coordination in the community
Sociology of professions	Professional-interprofessional congruity	Develop a collaborative culture in the community
Rewards	Team and collaborative efforts rewarded	Provide collaborative incentives for community stakeholders

Source: Tataw, 2011[56]

Elliott et al.[42] state that:

> Community dementia care is growing due to a combination of patient choice to remain in their home and the relative savings in costs compared with residential care. Despite the fact that the paid care workforce is one of the largest and fastest growing workforces worldwide, in Australia alone, there will need to be an almost threefold increase in aged care workers over the period 2010-2050...Finding ways to build the capacity of the existing workforce, while improving employee recruitment and retention rates in dementia care, is a paramount concern if we are to prepare for the predicted changes in the public health landscape.

Research by Elliott et al.[42] identifies themes that relate to the occupational experience of dementia care workers, and how the themes relate to capacity-building for community-based dementia care:

- Occupational communion – includes a sense of happiness and positivity in workers to participate in job tasks that are inherently based in social interaction;
- Job demands – workers are constantly expected to rise to challenges such as being alert to changes in care recipients and the environment, diverse practical care tasks, communicating with patients and family members, dealing with strong emotions such as grief and loss, and isolation; and
- Job resources – the ways workers perceive their work to be supported by both personal and organisational factors.

The research by Elliott et al.[42] concluded that occupational communion and strong professional relationships 'are essential to a healthy and productive workforce' and are necessary for building capacity if future workforce needs are to be met.

Xyrichis and Lowton[43] state:

> The increase in prevalence of long-term conditions in Western societies, with the subsequent need for non-acute quality patient health care, has brought the issue of collaboration between health professionals to the fore. Within primary care, it has been suggested that multidisciplinary teamworking is essential to develop an integrated approach to promoting and maintaining the health of the population whilst improving service effectiveness. Although it is becoming widely accepted that no single discipline can provide complete care for patients with a long-term condition, in practice, interprofessional working is not always achieved.

Xyrichis and Lowton's literature review revealed two main themes as either fostering or preventing interprofessional teamworking in primary and community care.

Table 3: Themes derived from thematic analysis

Themes	Categories
Team structure	• Team premises • Team size and composition • Organisational support
Team processes	• Team meetings • Clear goals and objectives • Audit

Source: Xyrichis and Lowton, 2008[43]

Hackman[57] cited by Reeves[58] offers a model in which he describes five conditions that influence team performance:

- Collectively, the team has a compelling direction for its work;
- The team's structure facilitates collaborative work. For example, there is open communication between members of the team;
- The organisational context within which the team works is supportive;
- The team has access to hands-on coaching to help members maximise their performance within the work circumstances; and
- Members collectively responsible for the teamwork.

Reeves et al.[58] also suggest that:

> (The literature) mainly offers generic descriptions of teams and teamworking, which do not pay sufficient attention to the *interprofessional-ness* of teamwork. Given the role politics and economics played in the emergence of health and social care professions, interprofessional teamwork was founded upon imbalances of power and status. However, such issues remain largely untouched...A hierarchical notion (of teamwork) overlooks the complexities of delivering care, which requires interprofessional teams to adopt a *contingency approach*, dependent on particular needs, contextual influences and available resources.

The Interprofessional Education Collaborative Report of an Expert Panel[30] identified Core Competencies for Interprofessional Collaborative Practice, which includes 'Teams and Teamwork' in its four competency domains. The Report states:

> Learning to be interprofessional means learning to be a good team player. Teamwork behaviours apply in any setting where health professionals interact on behalf of shared goals for care with patients or communities. Teamwork behaviours involve cooperating in the patient-centered delivery of care; coordinating one's care with other health professionals so that gaps, redundancies, and errors are avoided; and collaborating with others through shared problem-solving and shared decision-making, especially in circumstances of uncertainty. These processes reflect increasing levels of interdependence among those embedded in teams, in microsystems like hospital units, or in and between organisations and communities.

Conclusion

At present there are over 321,600 Australians living with dementia and this number is expected to increase by one-third to 400,000 in less than ten years. Without a medical breakthrough, the number of people with dementia is expected to be almost 900,000 by 2050. An estimated 1.2 million Australians are caring for someone with dementia and it is the third leading cause of death in Australia.

Up until the 1950s, dementia was regarded as a form of insanity that required segregation from society by way of detention in workhouses, institutions or asylums. The decline of the asylum period in the 1950s has seen the prevention of admissions through the provision of community facilities, discharging of institutionalised patients and the establishment of community support programs. The gradual shift towards a person-centred approach to care has resulted in nearly two-thirds of people with dementia living at home.

The increase in prevalence of long-term conditions in Western societies, with the subsequent need for non-acute quality patient health care, has brought the issue of collaboration between health professionals to the fore. Within primary care, it has been suggested that interprofessional teamwork is essential to develop an integrated approach to promoting and maintaining the health of the population whilst improving service effectiveness.[36,37,40,41,43]

Further resources:

Department of Health and Ageing, available at: http://www.health.gov.au

Alzheimer's Australia, available at: http://www.alzheimers.org.au

Carers Australia, available at: http://www.carersaustralia.com.au

Acronyms

AIPPEN	Australasian Interprofessional Practice and Education Network
ASPIRIN	Acknowledge the problem; Situational analysis; Provide some solutions; Implement; Review the outcome; Inform stakeholders; Next steps
CJD	Cruetzfeldt-Jakob disease
FTLD	Fronto temporal lobar degeneration
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
IPE	Interprofessional education
IPL	Interprofessional learning
IPP	Interprofessional practice
LBD	Lewy body disease
LIPSERVICE	Language; Introduction; Privacy dignity and cultural issues; Subjective questioning; Examination; Review; Verdict; Information; Check understanding; End or exit
MSP	Malignant social psychology
PCC	Person-centred care
RO	Reality orientation
WHO	World Health Organization

Glossary

Adverse events	Injuries resulting in harm to a patient and caused by medical management rather than the underlying condition or disease of the patient.[59,60]
Alzheimer's disease	A progressive, degenerative illness that attacks the brain.
Dementia	A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. [35]
Human factors	The interaction of equipment and individuals and the variables that can affect the outcome.[18,19]
Interprofessional education	Occasions when two or more professions learn from, with and about each other to improve collaboration and the quality of care.[8]
Interprofessional learning	Learning arising from interaction between members (or students) of two professions. This may be a product of interprofessional education or happen spontaneously in the workplace or in education settings.[8]
Interprofessional practice	Two or more professions working together as a team with a common purpose, commitment and mutual respect.[8]
Malignant social psychology	The observation that many of the interactions those working in dementia care have with patients is unintentionally malignant or abusive and serves to disempower, patronise, mock or disturb those in their care.[36,39]
Mnemonic	Any learning technique that aids information retention, e.g. acronyms and memorable phrases.
Morbidity	The rate of incidence of a disease.

Occupational communion	A sense of happiness and positivity in workers to participate in job tasks that are inherently based in social interaction.[42]
Person-centred care	The basis of person-centred care is understanding the importance of supporting an individual's personhood, and recognising and responding to each person as a human being, with a unique identity and worthy of respect.[36,39]
Reality orientation	RO techniques are based on repetitive presentation of information regarding time, place and person.[36]
Simulated learning environment	A technique, not a technology, to replace or amplify real experiences with guided experiences, often immersive in nature, that evoke or replicate substantial aspects of the real world in a fully interactive fashion.[1]

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