This timely text highlights the importance of informed and cri
practice in social work with older people. With an emphasis on r
throughout, it argues for the need to rethink how social workers
some of the most vulnerable people in society.

The text begins with an exploration of the relationship betwee
gerontology, the study of ageing, and social work, and demonstrates
that a gerontological approach has long been missing from social work
practice. The central chapters consider key issues affecting older people
and social work practice, such as:

- risk of poverty
- memory loss and dementia
- palliative and end of life care
- loss and bereavement
- moving into a care home

Bringing together theoretical and research insights, this agenda-setting
text provides a sound base for creative practice with older people. All
those looking to make a positive and discernible difference to older
people will find this text rewarding reading.

Mo Ray is Lecturer in Social Work at Keele University, UK, and
Postgraduate Director of the Masters in Social Work Programme.

Miriam Bernard is Professor of Social Gerontology and Director of the
Research Institute for Life Course Studies at Keele University, UK.

Judith Phillips is Professor of Gerontology at Swansea University, UK,
and Director of the Older People and Ageing Research and Development
Network in Wales. She is President of the British Society of Gerontology.
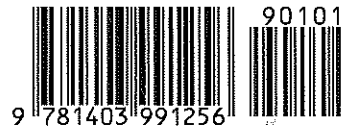
Mo Ray, Miriam Bernard
and Judith Phillips

Critical Issues in Social Work with Older People

Critical practice also necessitates practitioners having a sound *knowledge base* of the theories, policies and practices relevant to their practice context (Brechin, 2000). Historically, social work with older people may have been justifiably accused of lacking in well-established theoretical perspectives. It has also been the case that theories that have informed social work practice have tended to focus more on dysfunction and reinforcing perceptions of older people as dependent. As already noted in Chapter 1, there remains a tendency to construct social work with older people around the 'problem' of ageing. In order to avoid replicating experiences of oppression and discrimination grounded in assumptions about inevitable dependency, critical practice seeks to avoid operating in a framework dominated by pre-prescribed and proceduralized tasks.

Moreover, older service users are well placed to reflect on the experience of social work practice, and to ask questions about practices that may have a fundamental influence on their lives (Beresford, 2007a). Developments in listening to the opinions of older people, as a vital component in the growing evidence base for social care, exemplify such positive practice (Allan, 2001). However, the silence of some older people who are particularly vulnerable to life course inequalities becoming more acute in older age remains a crucial issue (Scharf et al., 2005). Consequently, given some of the limitations of traditional social work with older people, we would argue the need for it to draw more extensively than it has to date on the insights from social gerontology in general, and from critical gerontology in particular. It is to these perspectives that we now turn.

Critical gerontology

As with many labels, critical gerontology, like critical social work, is a contested term, and there is as yet no universal agreement on its definition. One definition that we suggest captures the essence of this approach comes from the work of Ruth Ray (1996, p. 675), who defines critical gerontology as: 'a critique of the social influences, philosophical foundations and empirical methodologies on which gerontology as a field has been historically constructed'. This alerts us to the importance of understanding the kinds of social, economic and political forces that promote critical perspectives (in whatever field), as well as the values that might underlie such approaches. It also sensitizes us to consider what might be the most appropriate ways of engaging with, and researching, the lives and needs of older people. In addition, back in the late 1980s, Phillipson and Walker (1987, p. 12) defined critical gerontology as 'a more value-committed approach to social gerontology – a commitment not just to understand the social

construction of ageing but to change it'. This emphasis on 'change' and, indeed on action, is one with which social work practitioners, as well as (some) researchers, might well identify.

However, these apparently simple conceptions belie the complexity of critical gerontology's origins and its implicit value base. Critical gerontology, like critical social work, has grown out of the broader critical social science movement and builds on a variety of intellectual traditions and foundations (Achenbaum, 1995; Estes et al., 2003). A critical perspective suggests that we are often unaware of just how much society, and societal structures, oppress us as individuals. With respect to older people, critical gerontology argues that they have long been marginalized and ignored; that we need to look afresh at our beliefs about old age, old people and the ways in which we as individuals, and society in general, respond to them; and that the traditional theories and methods we have used to study ageing and old age might need to alter (Estes et al., 2003; Baars et al., 2006; Holstein and Minkler, 2007). A critical gerontological perspective seeks to explain how oppression and injustice occur, and how they affect older people; it attempts to make the voices of oppressed and very diverse groups heard (for example, older women, black older people, people with dementia and so on); and it tackles problems and issues that have largely been ignored by mainstream social gerontological work (Baars, 1991).

The origins of critical gerontology

Gerontology itself has only been recognized as a field of study for a little over a century, the term first being used in 1903 by the Russian-born biologist Elie Metchnikoff (Achenbaum and Levin, 1989). However, it was not until the 1940s that the first professional and academic society, the Gerontological Society of America, was founded. This society brought together researchers, teachers and practitioners who worked with, or studied, older people and old age. These early developments during the first half of the twentieth century also spawned a whole range of what Achenbaum and Levin (1989) have called 'gerontology's specialties', including applied gerontology, experimental gerontology and social gerontology. Critical gerontology followed these developments and emerged in 1988, largely as a response to concerns about mainstream social gerontology's failure to challenge adequately the dominant decline and loss paradigm (Holstein and Minkler, 2007).

Paradoxically, then, gerontology is still a relatively new and developing field, and critical gerontology, as defined above, is an even more recent development. This means that it is sometimes difficult to

reach a consensus on what we may or may not consider comes within the scope of gerontology or critical gerontology. More accurately, perhaps, critical gerontology can be viewed as a set of perspectives that draw attention to the need to look at issues that go above and beyond conventional concerns and analyses (Baars, 1991; Achenbaum, 1997).

The development of critical gerontology

For much of the twentieth century, (social) gerontological research was couched within a primarily quantitative tradition with an emphasis on how older people should adjust to the challenges (and problems) associated with ageing (Estes *et al.*, 2003). Driven by demographic imperatives and the concerns associated with a developing welfare state, a primary aim of much early social gerontological research in the UK was to highlight and address the 'problem' of 'the elderly' and the 'burdens' posed by ever-increasing numbers of older people. Against a background of a 'secure welfare contract' between the generations (Means and Smith, 1998) and an expectation that the state would be the dominant provider of welfare, research began to document the poor living conditions and maltreatment of older people (Townsend, 1962, 2007) and particular concerns were raised about those living in special circumstances such as residential or psychiatric care. At this time too, the first large-scale surveys of the needs and circumstances of older people living in the wider community were beginning to highlight the extent to which people were being cared for outside institutional settings (Harris, 1968).

However, it was not until the 1970s that those working from within a political economy perspective – and following the Marxist tradition – began to raise crucial questions about how growing old was being experienced, and to show how our welfare system was effectively transforming ageing into a dependent status (Townsend, 2006). Political economists saw long-term care and community care as systems that reflected and bolstered the power inequities between experts such as social workers and lay people (Estes *et al.*, 2003). They further argued that the systems and structures set up by society, including professions such as social work, were essentially about controlling and managing people rather than providing them – in this case, older people – with opportunities for self-determination, rehabilitation and participation in everyday social life. Drawing on an alternative theory that emphasized 'structured dependency', the political economy perspective also stressed the ways in which public policies, and health and social services, were reinforcing this control and management, and deepening the dependency of older people (Townsend,

2007). One consequence of this growing critique (on both sides of the Atlantic) was that (some) gerontological research began to diverge considerably from the evaluative and service focus that, as we noted in Chapter 1, was evident in traditional social work research.

Critical gerontology, then, is rooted first and foremost within the political economy perspective. However, the inherent narrowness of this approach, with its overriding emphasis on the relationship between ageing and economic life, and on class inequalities, was challenged in the 1980s and 1990s by those working from within feminist and humanist perspectives. Feminist perspectives helped us to acknowledge the profound effects of life-long gender inequalities on the experience of later life (Arber and Ginn, 1991, 1995) and also led to a greater examination of diversity and difference encompassing racial and ethnic dimensions, disability and sexuality, and the power relationships within and between various groups. Additionally, the humanist perspective, which to date has developed far more in the United States than in Britain, has provided 'an approach to ageing which puts a human face – and a human body and spirit – on ageing and growing old' and encouraged us to explore questions such as 'what makes for a good life in old age?' and 'how can society support different visions of old age?' (Minkler, 1996, p. 470). Critical gerontology therefore seeks to raise vital questions, both about what we as a society *do* to older people, and about the *meanings* we attach to growing older and to old age itself.

Research from within a critical gerontology perspective has therefore diverged from more traditional social work research on older people in a number of crucial ways. Instead of the predominant evaluative and service focus we noted in the previous chapter, critical gerontology has provided us with research that has:

- Adopted a mix of methodological approaches and drawn on a wide variety of disciplines and theoretical perspectives to explore a range of issues pertinent to the experience of later life (Holstein and Minkler, 2007).
- Mounted a sustained critique of public policies and health and social services provisions affecting the lives of older people (Means and Smith, 1998; Townsend, 2007).
- Made the study of ageism, age discrimination and questions of intergenerational justice central to its research concerns (Bytheway *et al.*, 2007).
- Drawn attention to the significance of diversity and difference in later life (Estes *et al.*, 2003).
- Highlighted the strengths and resources people bring to old age, and moved away from pathologizing older people (Minkler and Fadem, 2002).

- Drawn attention to the search for meaning in old age and to what makes for a life of quality (Cole and Sierpena, 2006).
- Recognized and accepted the importance of qualitative and biographical methods in making visible the lived experience of older people (Bornat, 2000).
- Helped place older people at the centre of gerontological research and practice (R. E. Ray, 2007).

However, this is not to suggest that critical gerontology in and of itself provides all the answers to the challenges we face as social work practitioners and gerontological researchers. Consequently, before considering a framework for undertaking critical gerontological social work, we highlight some of the challenges that critical gerontology itself now faces.

Challenges for critical gerontology

Despite the progress made in critical gerontology since the 1970s, one trenchant critique has been that its two pathways – one drawn from the humanities and the other from the political economy/critical social science perspective – have tended to remain distinct and have operated in different domains (Ovrebo and Minkler, 1993; Holstein and Minkler, 2007). Recent critiques suggest that the failure to bring the two together means that we have been unable to get to grips adequately with what a 'real' or 'proper' critical gerontology should entail: what it should concern itself with theoretically and conceptually; what the experience of ageing is really like in the twenty-first century, and what it might become; and what research strategies, approaches and tools are most appropriate to illuminate simultaneously both the structural and individual aspects of ageing (Estes *et al.*, 2003; Holstein and Minkler, 2007). Indeed, American commentators Holstein and Minkler (2007, p. 19) have put the case for what they term 'a richer critical gerontology', which

> Calls for a deeper understanding of how perception, standpoint and value commitments affect all our work ... [and] encouraging what we are calling methodological bricolage, which requires crossing disciplinary and methodological boundaries so that ... the different pathways in critical gerontology can together enlarge understanding and systematically challenge the status quo.

Consequently, the first and most obvious set of challenges for critical gerontology is to look at how these two pathways can be brought together more effectively. In other words, how can what might on the face of it seem to be an individualistic approach stressing personal

growth, be seen as compatible with collective work tackling deeply embedded social, economic and structural inequalities? As Estes *et al.* (2003, p. 147) argue:

> Both require each other for a comprehensive understanding of contemporary ageing to take place. Structural approaches, without the humanistic element, offer limited insight into the humanity of the situations described. Without an understanding of social structure, however, an overly humanistic approach to ageing is isolated from context and history.

In the 1990s, Meredith Minkler (1996) suggested that one means of doing this might be to organize work in critical gerontology around a unifying concept such as 'empowerment' – a concept with which radical social work practice has also been associated. Despite empowerment being a much used and much abused term, Minkler (1996) and others (for example, Bernard, 2000) argue that it is useful precisely because it emphasizes notions of interdependence and is about acknowledging the ways in which we relate to, and can support, each other, as opposed to stressing independence or individual good above everything else. It impels us all to recognize that we live our lives in a social and political context, and that in order to fully understand both the commonalities and the disparities that exist, we need to look at the multiple ways in which people in general, and older people in particular, are disadvantaged and marginalized. If we can understand something of how environments and policies *disempower* people, we should be able to think more creatively (as researchers, educators and practitioners) about how we go about establishing situations in which older people can regain power and control over their lives. It means too that we can look at ways in which the capacity for empowerment and growth in old age can be facilitated and supported. This perhaps runs counter to how policy-makers might use the rhetoric of empowerment, where it is often seen as making individuals entirely responsible for their own actions, and a way of legitimizing cutbacks to communities and individuals.

More recently still, certain commentators have begun to argue for an approach to critical gerontological research and action that also lays greater emphasis on a 'human rights' perspective (for example, Feldman, 2002; Townsend, 2007). Such a perspective is premised on the unacceptability of discrimination against older people and the belief that all human beings, of whatever age and in whatever circumstances, have certain rights to things such as a reasonable standard of living. However, if bringing the two pathways in critical gerontology more closely together around a human rights perspective appears

complex and difficult, then this is precisely because it *is* and because, as Townsend (2007, p. 32) cogently explains:

> Rights are 'human' and not only civil or political. Rights are multiple and inter-dependent. Corrective anti-discriminatory measures have to be directed not at the separate existence of racial, religious, gender, disability or ageist discrimination but in a comprehensive, connected and proportionate manner against all forms of discrimination.

He also urges us to attend to the methodologies we use to uncover, measure and understand the impacts of human rights violations on people: 'not those only that end life, or involve extreme abuse ... but those that represent affronts to human dignity and identity' (Townsend, 2007, p. 32).

Thus a second set of challenges for critical gerontology is related to *how* we conduct research. Townsend (2007) challenges us to reject – or at least look at and question – the continuing use of traditional, familiar and single indicators in favour of developing multiple indices that would expose more reliably and unambiguously violations of rights in later life (Walker, 2005). Alongside this, a critical gerontology, organized along human rights lines and with empowerment as a central organizing concept, allows us to engage in more detailed examinations of how ordinary, everyday people live out their lives. As we have noted elsewhere (Bernard *et al.*, 2000), a key tool in this endeavour is the increasing use of biographical and narrative approaches in extending our knowledge and understanding about individual and shared aspects of ageing (Bornat, 2000; R. E. Ray, 2007).

Embracing both human rights and empowerment in research terms also means that, just as we might espouse the centrality of older people's views in terms of social work practice, so must we seriously consider the involvement of older people in the entire research process: from deciding the research questions to taking part in the different stages of the fieldwork, and to analysis, writing up and dissemination (M. Ray, 2007). Allied to this is the need we have already noted, to be critically reflective and self-reflexive in both research *and* practice: what Chamberlayne and her colleagues (2000) have argued as the importance of understanding something of our own histories and how we have come to be what we are, if we are to fully understand those with whom we work.

Moreover, biographical, participatory and reflexive research practices are only some of the methodological elements needed to bring together the two pathways in critical gerontology. Beyond this, it is important not to dismiss the insights we might obtain from other kinds of research: what Holstein and Minkler (2007, p. 22) have argued as the necessity for 'methodological bricolage':

> Methodological bricolage means not ruling out knowledge that is gained from personal narratives, fiction, poetry, film, qualitative investigations, philosophical inquiries, participatory action research and any other method of inquiry we may discover that yields insights into fundamental questions about how, and why, we experience old age in very particular ways.

This call for methodological bricolage, in turn links closely with a third set of challenges that have to do with articulating our value base and how we work with older people in professional capacities. And this links directly back to the values, skills and knowledge needed for good social work with older people, providing a direct bridge to the framework for critical gerontological social work outlined below. Thus a critical gerontology perspective with human rights, empowerment and methodological bricolage at its centre means that instead of 'doing to' older people in a detached and value-free way, we need to look at ways of 'working with' them in effective partnerships: in research, education and practice contexts. This is vital not least because, unpalatable though it may be, ageism and discrimination is alive and well amongst those who care for older people in professional capacities (Stevenson, 1989; Help the Aged, 2007; Milne *et al.*, 2007). Indeed, professionals who work with older people often hold some of the most negative and ageist attitudes of all – compounded, in many instances, by this being inflicted on older women by other women (Bernard, 1998). It is therefore important not only to draw attention to the evidence for these attitudes and practices, but also to stress the crucial role that reflexivity plays in a critical gerontological perspective. As ageing women (and men), we argue that it is necessary to explore and question our own values, assumptions and motivations – not to be self-indulgent but to enable us to clarify our understandings about what we do and how we do it, in order to become better practitioners, educators and researchers.

A framework for critical gerontological social work

By building on the things we value about good social work with older people, and drawing this together with critical gerontology, we can now begin to articulate what a more robust and critical gerontological social work approach might look like. The current requirements for social work training (Department of Health, 2002c) make clear

that *all* students should gain an understanding of the life course, and of intergenerational and systemic perspectives. Requirements also stipulate that service users should be involved in the design, development, delivery and assessment of social work degrees. Clearly, then, there are opportunities for all levels and aspects of professional training, education and practice to address and be underpinned by the kinds of anti-oppressive, critical and gerontologically informed principles and evidence we have been discussing. Critical gerontological social work therefore needs to be both about what we do (in terms of content) and how we do it (both academically, and as professionals and practitioners). In subsequent chapters we focus on crucial areas of substantive concern, including risk and frailty, dementia, end-of-life issues and informal care. However, underlying these key areas, a framework for critical gerontological social work must first revisit the values, skills and knowledge necessary for working with older people in the twenty-first century. And these, in turn, have implications for practice, for research, and for education and training.

Underpinning values

As has already been noted, leading proponents of the critical gerontology field have long argued for a more value-committed approach, and recognition that researchers, academics and practitioners cannot, and should not, stay aloof from involvement in social change (Phillipson and Walker, 1987; Estes *et al.*, 2003). These values have been articulated in our earlier writings (Bernard and Phillips, 1998, 2000; Bernard *et al.*, 2000; Bernard, 2001) but we reiterate them here so that readers are at least aware of – even though they might disagree with – our particular standpoint.

For us, the critical gerontological social work we engage in, whether it is from an educational, practice or research perspective has necessarily to be informed by commitments to:

- Social justice and intergenerational understanding.
- Countering stereotypes and combating myths and discrimination.
- Empowerment, citizenship and human rights.
- Pluralist and preventive views of ageing.
- Understanding oppression: its multiplicity and diversity (racial and ethnic, gender, disability, age and sexuality).
- Making experience visible through the words of older people themselves.
- Developing a critically reflective, and self-reflexive approach to ageing – both our own and that of those around us.
- Negotiating understandings and recognizing the existence of multiple perspectives.

- Working creatively with older people at the interface between preserving autonomy and independence in the face of declining physical and cognitive powers.
- Actively participating in making known policies, legislation and practices that are oppressive or which reinforce or maintain stereotypes, myths and discrimination relating to older people.

Clearly, articulating one's value base is a political act, since it locates social workers in a particular relationship to what and whom are being researched or worked with. In our view, this is a vital first step along the road to developing critical gerontological social work. It needs to be articulated, recognized and affirmed because, as Holstein and Minkler (2007, p. 19) argue, we all view the world and undertake our research, practice and educative work 'with a view from somewhere'.

Skills for critical gerontological social work

Rather than delineating a shopping list of skills, it is our contention that critical gerontological social work needs to develop, preserve and build on the kinds of skills social workers already use to facilitate positive and beneficial outcomes for older people. We know from the research evidence that the skills that are vital for good social work with older people include being able to:

- Form and develop positive and effective relationships between a social worker and an older person.
- Challenge a focus on medical perspectives at the expense of other aspects of an older person's life.
- Provide information to older people to enable them to make choices and decisions.
- Work creatively with ethical dilemmas such as risk against rights and conflicting agendas between an older person and their carer.
- Remain committed to the well-being of older people in the face of very considerable change and uncertainty.
- Recognize diversity, and challenge the tendency to treat older men and women as a homogenous group.

These skills, underpinned by a gerontological knowledge base, can help to ensure, for example, that social work assessments and interventions are geared towards the individual person's needs, rather than merely offering 'off the shelf' solutions. This in turn is bound up with recognizing that older people do not simply become passive recipients of care and support services, but that they seek actively to manage the challenges that might be associated with increasing impairment. Older people often utilize strategies, strengths and resources that have served them well throughout their life course,

and ensuring that these resources and strengths are considered alongside needs and difficulties creates the possibility for a different narrative about older people who use services. In order to create a different narrative, gerontological social workers must also have a sound understanding of terms that practitioners often use uncritically, such as frailty (Grenier, 2007); risk (Kemshall, 2002); and dependency (Johnson, 1979, 1990). These issues are returned to in detail in subsequent chapters, but lead us here into a consideration of the knowledge and skills that underpin practice. As an illustration, the example in Box 2.1 highlights ways in which social work practitioners can integrate an understanding of critical issues in social work with older people with achieving a user-centred approach to assessment practice.

Box 2.1 Research into practice: assessment skills

Richards (2000) undertook ethnographic research that explored the ways in which social workers approached assessment with older people. Richards identified a number of key social work skills that were critical in facilitating older people to explore and clarify their situations, talk about their subjective experience, and be aware of the range of options potentially available to them. Crucially, she noted that skilful assessors used different skills, depending upon the context of the older person and the degree to which the older person knew what he or she wanted to gain from the process.

Additionally, Richards highlighted the importance of social workers being able to conceptualize and maintain a distinction between user-centred and agency-centred elements of assessment. Attention to narrative enabled practitioners to work positively with older people to identify needs accurately and reduce the power imbalance as the social worker strove to engage with the older person's perspective. Richards (2000) highlighted that:

> Working with elders in a way that recognizes the individuality and complexity of their needs, that deals appropriately with conflicts of interest between elders and their carers, that achieves an essential clarity of task and fulfils agency objectives is skilled social work indeed. (p. 48)

Knowledge base

The final area to revisit in setting out a framework for critical gerontological social work is to look at its knowledge base and at the

gerontological research and scholarship that underpins this approach. One example will serve here to illustrate what we mean by this. A recent study by the Older People's Steering Group (2004) highlighted that older people value practitioners who are able to:

- Widen their approach from an assumption of the deficit model of assessment, and for intervention outcomes to move beyond the dysfunction perspective.
- Work in partnership with an older person as a means of changing the balance of power.
- Recognize and build-in the strengths and resources of an older person.
- Value what older people value (and have proper regard for the subjective experiences of older people).
- Facilitate active participation by older people.

These findings about what older men and women value in social work practitioners clearly resonate strongly with the themes coming from within critical gerontology. In turn, they suggest to us that practitioners might be able to strengthen their practice in a number of ways if they were to become more aware of, and could use the insights from, critical gerontology. If older people do indeed value practitioners who adopt these empowering ways of working, then these ways of working can be bolstered and reinforced by attention to the range of theories and perspectives which now provide a coherent critique of the multiple experiences of, and approaches to, ageing and old age. This body of evidence would assist practitioners to identify and challenge traditional myths about ageing and the stereotypical images younger people have about older people; to explore how society creates a sense of powerlessness in old age; and to understand how ageism manifests itself in all sorts of ways in our society – in the vocabulary used, in society's visual imagery, in institutional policies, and in discriminatory structures and practices (Butler, 1980; Johnson and Bytheway, 1993). The knowledge base underpinning critical gerontological social work also has implications for thinking about the kinds of ethical questions and dilemmas that practitioners face.

Conclusion

Alongside the well-established skills we know are vital for good social work with older people, twenty-first-century critical gerontological social workers need to be able to articulate their values, and their knowledge and skill base, and be confident in the contributions that they make, both to the lives of older people who use services, and to other professionals they are likely to work alongside. We know what older men and women value in social workers, and we can use the

ever-widening critical gerontological evidence base to reinforce and bolster best practice and education. We therefore see that developing the skills of research awareness and research mindedness, both at qualification and during later professional development, is a key component of critical gerontological social work. By bringing together theoretical and research insights from critical gerontology with the best elements of social work theory, research and practice with older people, it is our hope that the two can be integrated into a sound basis for creative practice with older people. In the following chapters of the book, we aim to show how we can no longer ignore these difficult challenges if, as we hope, social work with older people is to be accorded its rightful, but long overdue, place in the twenty-first century.

stop and think

- What do you understand to be the key principles of 'critical gerontology'?
- How could the gerontological knowledge base contribute to and develop social work practice?
- What knowledge, skills and values can you identify that are crucial in developing your critical gerontological practice?
- In what ways might age-based discrimination impact on the quality and range of services an older person might receive?

taking it further

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Risk and older people

main points

- Notions of risk are used to determine eligibility for services.
- Risk is a concept that may be used uncritically to label older people.
- Risk is often located at an individual level, whereas in reality, older people may be at risk from a range of structural, environmental and practical factors. These wider understandings of risk may be overlooked in practice.
- Critical practitioners have a duty to engage in a deep understanding of risk in order to enhance their interventions with older people.

Introduction

The preceding chapters have presented the case for retaining what we most value about good social work with older people, but developing it into a more robust, challenging and explicitly critical approach. In this chapter, and the ones that follow, we now turn our attention to areas we regard as crucial to the practice of critical gerontological social work in the twenty-first century. We begin with an exploration of risk and, in subsequent chapters, go on to consider dementia, end-of-life care, transitions and care-giving.

Concern about risk has found heightened expression in the current context of health and social care practice and policy. Whether we are conscious of it or not, social work practice with older people often involves defining and constructing them as being 'at risk' and evidenced by conceptions such as 'frailty' or 'dependency'. Working in a climate of constrained resources, risk has inexorably become central to defining eligibility for receipt of support services, as well as

Risk assessment, as part of critical gerontological social work practice should therefore be based on clear analysis and grounded in theory and research in order to encourage a risk-taking rather than a risk-minimization approach (Tanner, 1998). This shifts the focus towards defensible rather than defensive practice and, unless there is some toleration of risk and uncertainty, practice will inevitably be oppressive and defensive (Braye and Preston-Shoot, 1995). Practice should also incorporate a broader approach to risk management which, Alaszewski (2000) argues, should seek to balance potential negatives/harmful consequences against anticipated benefits, taking into account relative probabilities. Furthermore, risk assessment should seek to work in partnership with an older person in order to establish the perceptions that older people have about the risks they face in their daily lives. It is also critically important to determine the strategies that older people use to cope and manage, and to identify what a person may wish to retain or hold on to in their daily lives. A partnership approach between an older person and the person undertaking an assessment, is more likely to establish the actual (or potential) strengths and resources an older person has that might either mitigate risk, or be used as part of a risk-taking/risk management strategy. Balancing people's rights to autonomy against the risks they face should be a product of multi-disciplinary assessment that includes service users. This broader view of risk and risk assessment will, in turn, feed into other areas where social workers come into contact with older people, in both institutional and community settings.

Good risk assessment practice should therefore:

- Evidence the risks a person experiences.
- Analyse the risks in relation to potentially desirable outcomes and against potentially negative outcomes.
- Analyse the risks in relation to the strengths and resources that do (or may) mitigate the risk.
- Garner evidence from the older person, relevant social networks and other people involved in the formal care system.
- Be able to make informed decisions and choices/capacity.
- Be carried out with the best interests of the older person uppermost.
- Identify the least disruptive intervention needed to manage/take risks.
- Properly record risk management/risk-taking strategy and intervention plan.
- Put in place a review and monitoring framework.
- Make appropriate use of the provision for the protection of vulnerable adults (see Chapter 8).

Risk and institutional care

Although admission to care homes may be experienced by many older people as a positive choice and an opportunity to receive care and assistance in a supportive and homely environment, it is more commonly seen by professionals and family members as a way of managing unacceptably high levels of risk and ensuring the person's safety. All too often, older people with complex needs have moved to a care home because the inadequate or poorly developed resources to enable them to remain safely at home have been exhausted. Research by Housing 21 (Vallely et al., 2006), examining housing biographies for older people with dementia, concluded that a diagnosis of dementia is not the primary reason for admission to residential care. Instead, premature admission is often caused by fragmented services, the complexities of long-term funding, and lack of expertise and experience in tackling so called 'challenging behaviour'.

In addition, moving into a care home can happen in situations of pressure or emergency, and it is perhaps easy to overlook the potential risks associated with the very course of action that was intended to reduce or remove risk. Pritchard (1997) cites a number of examples of what might happen to an older person who now finds him/herself in institutional care:

- Being in an unfamiliar environment (lost and disoriented).
- Loss of remaining skills.
- Emotional distress.
- Isolation and loneliness.
- Depression.
- Loss of existing social support networks.
- Inappropriate care.
- Abuse.
- Loss of identity.

As research has also shown, there are further risks associated with inappropriate medication of older people in care homes (CSCI, 2006c). Older people with dementia, for example, are one group of people who may be particularly vulnerable to the overuse of neuroleptic (anti-psychotic) medication as a way of treating symptoms such as agitation or aggression. The Alzheimer's Society comments that it: 'remains deeply concerned about the overuse of neuroleptic drugs for people with dementia in care homes. The over-reliance on pharmacological treatments for behaviour such as wandering or agitation, can be the result of lack of training in dementia care' (www.alzheimers.org.uk). Moreover, as recently as 2006, the Commission for Social Care Inspection (CSCI, 2006c) reported that half of all care homes in England, providing 210,000 places for residents, many of whom are

older people, do not meet minimum standards in the management and administration of medication. Current poor practice constitutes significant risk and potential harm to older people, including:

- Evidence of wrong medication given to residents.
- Poor recording of medicines received and administered.
- Inappropriate handling of medicines by untrained staff.
- Medicines being stored inappropriately.
- Poor achievement of six-monthly reviews for people prescribed four or more medications.

Such practice is also now regarded as institutional abuse (Select Committee on Elder Abuse, 2004) and must therefore constitute a significant risk for older people and an area of practice concern for gerontological social workers. The potential for ageist attitudes grounded in assumptions that nothing much can be done, together with poorly resourced and inadequately trained staff groups, cannot be discounted as possible causes of such poor practice. Does it matter, for example, if someone who is very ill misses a tablet? Should we be concerned if a resident is asleep for most of the day and can barely be roused to eat or drink? Evidence suggests that organizational and cultural changes are necessary to develop practice, reduce institutional abuse (inappropriate medication) and promote safe practice (CSCI, 2006c). Again, gerontological social work practitioners cannot remain aloof from these issues. They actively participate in helping older people to move into residential facilities and, at the very least, prepare an initial care plan. They are also often responsible for undertaking reviews of the placement and may be called upon to participate in reassessing a person's care needs if it is felt that the person's needs cannot be met in the care home.

A further area of concern for practitioners is where care homes struggle to provide worthwhile and valued activity for older people. Older people with dementia may be particularly susceptible to being under-occupied, as Perrin and May (2000) show in their research. Based on observational data, they stress the extreme occupational poverty of many residents and draw important inferences about levels of 'ill-being' and poor quality of life. A person with dementia living in a care home may well be left alone for much of the day and respond by sleeping and appearing to be socially isolated and disengaged. Is that person at risk because of their failure to stimulate and occupy themselves or because, at some level, it remains acceptable for some older people who are sufficiently powerless and invisible to live in a situation of extreme under-occupation and, therefore, institutional abuse?

Extract 3.2 illustrates vividly some of the consequences of living in the kind of institutional environment where opportunities to do some-thing interesting or worthwhile appear to be limited. As you read, consider what role you think social workers (and others) should have in ensuring that assessments and individual care plans include information about a person's lifestyle and interests? What action, if any, would you take if you came across the situation described in this extract?

Extract 3.2 *Occupational poverty and quality of life*

On Tuesday when I first went I could not find her. I went into the sitting room, looked around, could not see Grandma, could not think of whom to ask and so went in search of her ... There was no one about in any of the corridors. Wherever I looked, there seemed to be old women asleep and I started tip-toeing instinctively ... She was sitting [in the dining room], on her own, at a table for four ... Grandma was motionless, staring straight ahead, slumped in an attitude of total dejection. I rushed up to her, saying her name, but there was not a flicker of response. I came right up to her and said, 'Hey, it's me,' and she looked straight at me with entirely blank eyes. It seemed to me that there was a faintly sickly odour about her and tiny flecks of what looked like foam in the corner of her mouth – but it was meringue, clinging to her incipient moustache. I wiped it away, far too energetically, still talking to her. It took a long time for any recognition to dawn and even then she did not know my name. I wanted to cry. I longed to go and shout at someone and blame them. But there was still no one about ...

Yesterday I went full of apprehension. I went later, reckoning I had gone at a bad time the day before, at the post-lunch time when most of the Birchholme ladies were snoozing. At least, this time, Grandma was not on her own. She was in the sitting room, ostensibly grouped with two other women, but they had pulled their chairs round so that their backs were to her. She seemed asleep when I arrived. When I whispered in her ear, she tried to swat me away as though I were a fly and said she couldn't be bothered. She told me to go away, she was fed up, she wanted to be left alone. I coaxed and wheedled and tried to humour her into opening her eyes. When she did, I was alarmed. Her eyes were red-looking and a small amount of pus leaked out of one corner. She looked at me as blankly as she had done the day before and then she said, 'How long is this going on?'
(Margaret Forster, *Have the Men Had Enough?*)
Seen from Jenny's perspective, pp. 182–4.

Risk and living at home

Of course, older people may also experience risk and harm as a result of living at home and, again, professional interventions may unwittingly worsen rather than alleviate these risks. For example, McCarthy and Thomas (2004) highlight the ways in which an excessive focus on the principles in 'Best Value' can lead to interventions that create and reinforce experiences of social isolation and loneliness: delivering frozen food once a fortnight for an older person to reheat in their microwave may achieve a target for Best Value, but the potential hidden cost of loneliness and isolation may well outweigh any savings incurred from this intervention. Furthermore, social isolation, linked with a lack of meaningful activities and social opportunities, may contribute to earlier admissions to care homes, especially for older people with dementia (Vallely et al. 2006). Research has emphasized increasingly the importance of meaningful activity and occupational identity in person-centred care (Perrin and May; 2000; Bell and Troxel, 2001) but, it remains the case that, all too often, insufficient attention is paid to the occupational identity of older people, and in particular those persons with dementia. Social workers can make a vital contribution to identifying, in both assessment and care planning, the occupational identities and the sorts of things an older person likes to do with his or her time.

Conclusion

The association of assessment and eligibility criteria has contributed to the biomedicalization of older people. Specifically, need is constructed as risk (and danger) as a means of confirming that a person is eligible to receive finite and limited services. Risk all too often is defined as 'individual risk', and being 'at risk'. This perspective fails to take into account the fact that older people may experience considerable risk from wider social and structural factors, and that the risks they face may have little to do with an individual orientation. Social workers' commitment to a critical perspective can be helpful in considering ways in which an anti-oppressive stance can resist practices which may increase or, at the very least, reinforce structural and socially situated risks.

Increased managerialism has also led to a tendency towards being 'risk averse'. This can create messages for practitioners about older people being essentially passive, and can discourage an acceptance that the right to take risks is part of the lives of all of us, and often adds to our quality of life and sense of identity. The importance of working in partnership with older service users who may experience

a range of risks, as well as recognizing the existence of other perspectives that are likely to be at variance with these, calls for considerable social work skill. Risk-taking strategies require practitioners to assess evidence or information about the likelihood of the risk leading to an undesirable outcome, and the actual (or potential) resources that can be used to support the risk. This practice has to be undertaken with careful consideration of Human Rights legislation and capacity. The involvement of service users in evaluating services and professional support seems to be a critical factor in discouraging managers and practitioners from erring towards a risk avoidance approach to practice. The importance of evaluating practice and learning from such evaluations is also crucial, as it remains the case that the evidence base on risk-taking and ageing remains relatively under-developed. Social work practitioners, by using practice as an opportunity for learning and development, can augment local knowledge and expertise about 'what works' in risk-taking and risk management, as well as identifying areas for the commissioning of support services and resources.

stop and think

- Reflect on how you like to spend your time (for example, the hobbies or activities you enjoy). What does participation in those activities contribute to your sense of well-being and a sense of who you are?
- How might you seek to address the risks that an older person might encounter in moving to a care home?
- How can social workers contribute to reducing the risks that might be associated with living on a low income?
- How can you find out how a care home approaches the role of activities and occupation in promoting quality of life and well-being?

taking it further

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4 Social work with older people with dementia

- There has been a considerable development of interest in research, policy and practice relating to people with dementia. Nevertheless, people with dementia remain marginalized and often do not receive the range of support, services and interventions that they need to promote and maximize their well-being.

- Social workers have a crucial role to play in assessment, intervention and care planning with people with dementia and their carers.

- Social workers need to have an understanding of the knowledge and skill base that would support positive practice with people with dementia.

- Good practice means challenging the potential for practice to be reduced to bureaucratic procedures.

Introduction

This chapter focuses on an area of growing concern, by exploring how a gerontological social work approach might help to address the needs of older people with dementia. Traditionally, dementia has been located within a biomedical perspective, influenced by the drive to diagnose the cause of the illness and provide medical treatment to address and manage symptoms. At the time of writing, however, dementia is not 'curable', leaving aside so-called 'arrestable' dementias. Dementia has also largely been understood in terms of irretrievable loss and impairment, and as a personal tragedy for the individual and those closest to them. In this context, people with dementia

have been perceived and constructed as 'victims' of an incurable disease that would inevitably rob them of their personalities, identities, insight and abilities. As a result, traditional care cultures emphasize physical tending such as keeping the person with dementia clean, fed, warm and dry (Kitwood, 1997). Moreover, in policy and practice terms, people with dementia (and people involved in their care and support) have experienced a legacy of marginalization and oppression. Little attention has been paid, for example, to developing creative housing options for people with dementia (Vallely et al., 2006), and social and health care services are often poorly developed, patchy and fragmented.

Since the mid-1990s, however, significant interest has developed in research, practice and policy around dementia and dementia care. It is this body of work that we draw on in this chapter, and that we argue should underpin critical gerontological social work with older people. Consequently, the chapter begins by reviewing briefly the biomedical approaches to dementia care, before discussing the development of interest in person-centred approaches. We then consider other key theoretical developments as well as structural, biographical and rehabilitative work, which, together, have widened our understanding of dementia and contribute to the agenda for future practice and service development. Finally, the chapter raises a number of important challenges around developing critical gerontological social work practice with older people with dementia.

Biomedical perspectives

Dementia has long been located within a biomedical perspective and this, in turn, has often meant that a person's behaviour was most likely to be construed as a manifestation of cognitive decline. However, biomedical perspectives also differentiate between the normal changes in the brain associated with cell death, and impaired function of cells associated with a diagnosis of dementia (McKeith and Fairbairn, 2001). Alongside this, and given the greater preponderance of dementia in older age, it is also important to distinguish between 'normal' and 'abnormal' ageing. Clinical studies suggest, for example, that a 70-year-old, normally-ageing person will experience some cell death, but this will not have any impact on existing knowledge, although it may have some impact on learning new skills (McKeith and Fairbairn, 2001). Moreover, the prevalence of dementia at age 75 is currently estimated to be 10 per cent of the population, doubling every five years (for a full discussion, refer to Gauthier, 2006). However, these estimates fail to take into account people experiencing cognitive impairment who may be 'hidden' (for

example, in care homes) and have not sought help or diagnosis, or who have not been referred for specialist assessments and diagnostic investigation. In addition, stigma associated with cognitive impairment may well prevent people from approaching general practitioners (GPs) for further investigation (Manthorpe and Iliffe, 2007). Once the GP has been consulted, however, research from the National Audit Office (formerly the Audit Commission) (2000) has shown that there is also evidence of GPs failing to refer older people with cognitive difficulties to secondary specialist sources, as well as failing to identify presenting symptoms such as memory loss, as potentially being caused by dementia.

These kinds of barriers are problematic, not least because we know that a diagnosis of dementia can be crucial in unlocking services, interventions and symptom modification, such as anticholinestarase medication (Marshall and Tibbs, 2006). At the time of writing, formal diagnostic procedures focus on clinical history, establishing the existence of treatable conditions, physical examinations and cognitive function tests. Cognitive function is also commonly tested alongside an assessment of the impact that cognitive impairment has on a person's daily living activities (Maciejewski, 2001). However, the perception of people with memory difficulties who have been cognitively assessed suggests that the process is often disempowering, frightening and confidence-sapping (Keady and Gilliard, 2001). Moreover, diagnosis may not be certain, and so follow-up may be necessary in order to assess the development of symptoms over time.

In addition, a diagnosis has other implications in that the diagnostic label 'dementia' may well influence the ways in which the person is subsequently responded to (Manthorpe and Adams, 2003). As an illustration of this, consider Extract 4.1, in which a diagnosis of dementia is given to Bridget about her mother. What principles of good practice do you think should underpin sharing a diagnosis of this nature? Once a diagnosis has been given, what are the implications of such a diagnosis for the person with dementia, and for their families/supporters?

Although multi-agency assessment, care planning and intervention are becoming increasingly better developed, sociological analysis still highlights the medicalization of dementia, the mandate to *treat* people with dementia, and the persisting monopoly of medical knowledge (Bond, 2001). The central focus of a biomedical model is therefore for disability to be located as *an individual* problem, evidenced by the functional limitations of people who are impaired (Swain *et al.*, 2003). Moreover, the collective experience of oppression that people with dementia may experience is overlooked in favour of identifying individual problem states and treating the individual.

Extract 4.1 *Diagnosing dementia*

[Dr Carruthers – the geriatrician] came and spent an hour with Grandma on his own and then he wrote a report. Bridget said she could have written it herself, it was so obvious, but we found it helpful. Grandma, the report said, was suffering from moderate senile dementia. She knew her name, her age, the names of her children and grandchildren, and where she was living. She could feed herself, toilet herself and walk unaided. But her sense of time had gone. She did not know the date or the year or who was Prime Minister or Queen. She did not know whether she had eaten today or not. She had no sense of direction. The prognosis was carefully worded: with the family support she was getting it was perfectly possible that the dementia might get no worse for several years. Charlie rang up Dr Carruthers to ask the crucial questions: was it inevitable that eventually it would get worse? Yes. And how long did the process usually take? Five years. What happened after that? Death.
(Margaret Forster, *Have the Men Had Enough?*)
Seen from Jenny's perspective, pp. 35–6.

Social models and dementia

In order to address some of the criticisms of the biomedical perspective, it has been argued that dementia should be seen in the context of a social model of disability. This alternative to the biomedical model was first developed by disabled people themselves (UPIAS, 1976) and defined impairment and disability in these terms:

- *Impairment*: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body (later, this definition extended to include cognitive impairment and emotional distress).
- *Disability*: The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

These definitions highlight the fact that disability can constitute exclusion from full participation, which is neither inevitable nor necessary, and as a result disabled people are an oppressed social group

(Priestley, 2003). In a social model, disability is reconstructed as a social and political process, created by societies and the way they are organized to suit the needs and requirements of non-disabled people. The development and increasing acceptance of the social model of disability has been a powerful and important means of drawing attention to the experiences of oppression, marginalization and exclusion that are commonplace for many disabled people and, by extension, for many people with dementia and other socially disabling conditions.

A further achievement of this model is that it has highlighted the importance of a collective identity as a means of challenging oppression (Campbell and Oliver, 1996), which also acts as a foil to the focus on the individual in diagnosis and treatment within a biomedical model. Adams and Bartlett (2003) acknowledge that the notion of a collective identity for people with dementia may appear to be counter-intuitive to the efforts that have gone into promoting the importance of each person with dementia as having a unique biography and identity. However, they further argue that an understanding of the collective impact of oppression should not preclude the consideration of the individual person's journey in dementia, his/her unique identity, and individual care and support requirements. In other words, they espouse an approach that brings together the awareness engendered through the social model of disability, with the person-centred approaches to dementia that have gained considerable ground in recent years.

The development of person-centred approaches to dementia

Person-centred approaches to dementia are synonymous with the work of Tom Kitwood, who, in the early 1990s, first began to offer a robust and critical challenge to the dominance of the biomedical perspective (Kitwood, 1993, 1997). While acknowledging the important contributions of medical science, Kitwood's concern was that, in the quest for medical dominance, personhood was often overlooked, particularly with regard to people who could not easily speak for themselves: 'It has become all too easy to ignore the suffering of a fellow human being, and see instead a merely biological problem, to be solved by some kind of technical intervention' (1997, p. 44). In Kitwood's analysis, the consequence was that dementia was constructed as a catastrophic loss of self, and care cultures developed to focus on physical elements of care with a focus on warehousing people in collective settings. The term 'malignant social psychology'

was coined to signify the damaging and harmful effects of care environments that undermined or diminished and neglected individual personhood. Using a critical incident technique, Kitwood identified evidence of malignant social psychology in the everyday care of people with dementia (for a full discussion, see Kitwood, 1997, p. 46–49). As you read Extract 4.2, reflect on the potential for loss of personhood and the challenges for people with cognitive impairment in sharing communal spaces. How might we move towards developing more positive social and physical environments? Consider also what you would look for if you were going into a care home for the first time, in the physical layout and design, the atmosphere and the approach/attitude of staff?

Extract 4.2 *Loss of personhood and objectification*

... it is the going into King's Wood which is the worst ... No one came forward to greet us but then it was tea time, everyone was busy. All the old women were seated round a table being fed. There were four staff for the twenty women. The noise was terrible – wild cawings as though a clutch of rooks had settled there. One woman banged all the time with a spoon on the table and another shouted, 'About bloody time! About bloody time!' over and over. I pushed Grandma to the table, glad that I was behind her and could not see her face. The four staff members, in yellow overalls, stared at us... I said we were expected. One of them went off, grudgingly it seemed, and came back with a small, squat woman in a blue and white uniform who said she was Sister Grice, and she was in charge ... While she addressed me, a white-haired, sweet-faced old woman got up from the end of the table and shuffled down to stand beside me. She put her hand on mine and made some sound I could not distinguish. 'Go away, Leah,' the Sister said. 'Go on, off with you, don't bother the lady.' I said she wasn't bothering me and asked Sister what she had been trying to say to me. 'She's deaf,' Sister said. 'Nothing she says makes sense, don't let her bother you. It doesn't bother us.'
(Margaret Forster, *Have the Men Had Enough?*)
Seen from Jenny's perspective, pp. 201–2.

Traditional ideas of personhood, such as those posed by Quinton (1973; cited in Kitwood, 1997) focused on consciousness, rationality, agency, morality and the capacity to form and maintain relationships. In contrast, Kitwood sought to embrace a definition of personhood

characterized by attention to feelings, emotions and living in relationship to, and with, other people. In order to keep personhood at the centre of a positive culture of care, Kitwood proposed that the individual person should be considered first and foremost, as opposed to allowing the label 'dementia' to subsume and overwhelm the person.

The 'doing' of person-centred care was not worked out in detail by Kitwood, and others have sought to develop person-centred care practice and also to offer refinements on the definition, construction and meanings of person-centred care. Rather like 'empowerment', person-centred care is in danger of becoming a catch-all term incorporating a range of definitions and practices. Brooker (2004) has identified four key elements that encapsulate person-centred care, but comments that these may be used singly or in combination. The elements she identifies are:

▪ Valuing people;
▪ Treating people as individuals;
▪ Seeing things from the perspective of the person with dementia; and
▪ Creating a positive social environment.

An examination of these elements highlights the critical challenges posed in achieving a person-centred culture. Social work environments increasingly focus on, for example, fast throughput of assessment work which is of itself often limited by a focus on dysfunction and problem states; difficulties in providing proactive and preventative services caused by the current emphasis on the highest levels of risk and need as defined by Fair Access to Care criteria; and a limited potential for continuity by practices that fragment 'cases' into different teams with increasingly narrow functions (for example, screening teams and review teams). Consequently, it is important to reorientate our views and understanding of dementia if critical gerontological social workers are to be enabled to support and advocate for older people and those who care for them in the most effective ways.

Widening our understanding of dementia care

Cantley (2001) has argued that, in a multi-agency context, the first essential step is for practitioners and managers to understand a range of theoretical perspectives relevant to their own and others' practice. Social work training and practice espouse the importance of working with individuals, but they are also concerned with the social, structural and economic systems within which individuals operate. Social workers wishing to engage in critical practice with older people should therefore be encouraged to consider additional theoretical

developments beyond the traditional approaches discussed so far. In this context, we now discuss the more recent extension of attachment theory to informing our understanding of behaviours associated with dementia. This is followed by a brief consideration of structural aspects, with a focus on ethnicity, before outlining recent developments in biographical and rehabilitative work, which have both contributed to widening our understanding of dementia and dementia care.

The role of attachment

The early work of Bowlby (1969) on attachment behaviours highlighted the ways in which attachment experiences between a child and his/her parent would have an impact on the child's emotional and behavioural development. In recent years, this work has been extended and developed to consider both the role of attachment in adult and later life (Antonucci, 1994) and the impact of childhood attachment experiences on later life attachment behaviours. Andersson and Stevens (1993), for example, argue that evidence suggests that early attachment experiences have an impact on attachment behaviours in later life. However, their research also indicated that the presence of important attachments formed in adulthood (such as a partner) could mitigate the effects of ambivalent/anxious or disrupted attachment experiences learnt through childhood experience.

Alongside these developments, there is growing interest in the role of attachment experience and behaviours in dementia. For example, Miesen (1992) has argued that, in severe dementia, the attachment behaviours a person may ordinarily have may be increasingly difficult to enact as memory, language and orientation become compromised. As a result, a person with dementia may seek comfort and security in past early relationships, which are often believed by the person to exist in the present. Deceased parents may therefore be identified as living, available and in a relationship with the person with dementia.

Other research has extended this understanding of attachment behaviours and explored the potential of simulated presence therapy (SPT) to provide comfort and security to people with dementia who are living in a nursing home (Woods and Ashley, 1995). SPT comprises audio-taped material, produced by a person close to the person with dementia. The material is made up of cherished memories, anecdotes and experience shared between the person with dementia and their loved one. Its rationale is that the voice of a person who represents a key attachment figure in the life of the person with dementia will promote well-being, encourage ongoing attachment behaviours

and reduce separation anxiety. Woods and Ashley's (1995) research was carried out with twenty-seven participants, and they found that the use of SPT had a significant impact on emotional state, evidenced by the person exhibiting positive behaviours such as singing, smiling, laughing and verbalizing. Results also suggested a significant impact by SPT on reducing behaviour such as social isolation, agitation and anxiety. However, this is a small sample and there is clearly a need for further research in the area of attachment and simulated presence therapy.

While the research base examining attachment and dementia is clearly an evolving one, Browne and Shlosberg (2005) identified a number of potential practice implications. They contend that it can help practitioners to understand why a person may be behaving in a certain way, and assist carers in planning positive support strategies. In addition, by encouraging support staff and carers to consider a person with dementia and their attachment style and past attachment experiences, it can help in understanding how a person with dementia relates to staff and carers. Finally, a basic awareness of attachment through training may help both carers and staff to respond more appropriately to the emotional meanings of so-called 'challenging' or 'confused' behaviour (Mills *et al.*, 1999, cited in Brown and Shlosberg, 2006).

Ethnicity and dementia

From both research and practice perspectives, it is important to acknowledge that people with dementia, like all older people, are also located in other structural contexts such as age, gender, sexuality, class and ethnic minority membership. A critical gerontological approach argues forcefully that an analysis of multi-faceted structural features is important to illustrate how other oppressions, such as racism, are experienced over the life course, and how these in turn impact on a person who is diagnosed with dementia. For example, there is now considerable evidence demonstrating a widespread lack of culturally appropriate services for older people from minority ethnic groups (Forbat and Nar, 2003). Members of minority ethnic communities may be rendered effectively invisible by services that are, in reality, geared to the needs of the dominant population. This, in turn, may be reinforced by a lack of understanding among such communities about what dementia is, and what it is like to live with, and care for, someone with dementia (Jutla and Moreland, 2007).

Iliffe and Manthorpe (2004) further highlight the contested nature of terminology used to discuss ethnicity, and argue that the primary

issue between ethnicity and dementia may relate more to the misunderstandings of professionals than to a precise relationship between the two. For example, services may be developed with an 'Asian' community in mind, but this generic term covers huge diversity and difference between and within religious and cultural groups. Citing the work of Alexander (2002), Iliffe and Manthorpe (2004) comment that notions of collectivity may render less visible the heterogeneity that exists within groups. In other words, attempts to provide culturally sensitive services based on an understanding of a group of people (for example, Sikh people) may result in promoting inappropriate assumptions about individuals, rather than addressing what is needed to provide 'tailored, wrap around services for diverse individuals' (Iliffe and Manthorpe, 2004, p. 289). This can further reinforce stereotypes such as 'Asian' people looking after their own. Anti-oppressive approaches support a practice that, rather than making professional assumptions, engages in a dialogue with the person. Such an approach recognizes the expertise and experience of 'the other' and seeks to ensure the inclusion of people in the process of negotiated interventions.

Biographical understandings

One important way of facilitating dialogue, which has gained considerable ground over recent years, is to develop an understanding of the individual person's biography and identity. Awareness of individual biography is important for a number of reasons. First, recognizing an individual as a unique person may help practitioners to keep that person at the centre of what they are doing and help to maintain personhood in the ways envisaged by Kitwood and others. Such an approach challenges the potential to respond to a person with dementia as just another member of an essentially homogenous group, whatever their ethnic or cultural background. Second, biographical information may enhance understanding of the person's individual context. How long a person has lived in his/her house; the person's interests and achievements; his/her family history; experiences of migration; and relationships with friends constitute essential information that may illuminate areas of strength and resources as well as those of need. Biographical information is also likely to provide insights into which aspects of a person's life that person would wish to preserve or maintain. Third, biographical information is a vital component in care planning. It is important for a person with dementia to have his/her habits, routines and preferences respected in planning care or support. This may not only contribute to helping the person feel secure, but may also ensure that he or she

continues to participate actively in their own lives. Finally, biographical information – especially where it can be linked with insights from attachment theory – can help to understand behaviour that may not be easy to understand, or is perceived as 'challenging'. Again, this may be crucial in helping formal and informal carers to provide sensitive support and assistance.

To illustrate the importance of biographical understandings, consider Extract 4.3. This reflects on the evocative power of smells, textures and sights in conjuring powerful images and memories of Mrs McKay from her granddaughter's perspective. If you were working with this family, how would you try to ensure that Grandma's memories were preserved? How could you capture some of this information in an assessment, and what would the challenges be of achieving this?

Extract 4.3   *Biographical understandings*

The house smells of Grandma when I go in ... Grandma is kept very clean but she just smells of being old. Just old. She's forgotten her tartan shawl. I pick it up from the sofa and bury my face in it. Mum comes in and says to give the shawl to her, it needs washing, that she shudders to think how many times Grandma has blown her nose on it and mopped up tea and used it to wipe dishes. She will wash it in Lux flakes and rinse it in Comfort and hang it in the garden to dry in the wind. In fact, she'll help Grandma to wash it and hang it out herself tomorrow, she'll love that. It's perfectly true. Grandma is passionately happy scrubbing things. I look at her, when Mum has her standing at the sink up to her elbows in suds, and I can always see Mum is right. Washing is women's work. It doesn't take Grandma back to backbreaking days of unremitting labour, when she had to heat the water in a copper and stand in a freezing wash house, oh no, it takes her back to a house full and never a lonely moment and a sense of purpose.
(Margaret Forster, *Have the Men Had Enough?*)
Seen from Hannah's perspective, p. 20.

A focus on rehabilitation

Alongside the now wider acceptance that biography and identity are important to our understanding of people with dementia, recent years have also witnessed much greater practice effort geared towards the rehabilitation of older people. Social work has contributed to the multi-disciplinary rehabilitative team in a number of ways; for example, undertaking components of multi-disciplinary assessment, participating in intermediate care plans, contributing to hospital discharge planning, and post-discharge care and support. Historically, however, people with dementia have not generally been linked to rehabilitative services. But there are some encouraging signs that this is beginning to change. Marshall (2005), for example, has identified four major strands of rehabilitation in respect of people with dementia which we regard as being crucial to widening our understanding of dementia and dementia care. She suggests that rehabilitation is important:

1. Following an acute illness, surgery or medical intervention.
2. After a period of 'challenging' behaviour (for example, a person being admitted for assessment to a specialist ward from a care home environment where their behaviour was identified as 'difficult to manage').
3. As a means of making the best use of brain function by cognitive rehabilitation; the emphasis is on an ability model rather than one of deficit.
4. As a positive approach to dementia care underpinned by the assumption that obtaining appropriate, timely and skilful assistance will contribute to better functioning and, potentially, quality of life.

However, while generic research examining outcomes and the effectiveness of rehabilitative effort is beginning to develop, there is still a paucity of research on the effectiveness of rehabilitation for people with dementia. Consequently, there is much that still needs to be done to continue to actively construct models of rehabilitation that are specific to the needs of people with dementia (Mountain, 2004). This, then, is one of many important tasks facing the development of critical gerontological social work practice.

Dementia and critical gerontological social work practice

Good practice guidelines in dementia care have been published jointly by the National Centre for Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) (NICE/SCIE, 2006). These guidelines include a commitment to the principles of person-centred care as the underpinning knowledge, skill and value base in dementia care. Paradoxically, however, an increase in awareness of the needs of people with dementia has not generally coincided with increases in

proactive support services. Consequently, those who subscribe to a critical gerontological practice orientation must contribute to making explicit the experience of dementia, and to promoting interventions that enhance quality of life and enable the active participation of older people with dementia in service development. In order to do this, we suggest that practice needs to focus on the challenges of improving communication, of appropriate assessment and care planning, and of effective partnership with informal carers: issues to which we now turn our attention.

The importance of communication

Despite the limited contribution that speech makes to the totality of human interaction, we have a long socialization in the importance of verbal communication. In our day-to-day lives, value is placed on our ability to communicate verbally: we tend to value eloquent expression, the ability to build a coherent argument, debate a case and, as a result, receive positive outcomes such as validation of identity, respect and access to resources. Language also communicates information about power and the ways in which hierarchical relationships are maintained and characterized by the possession of resources such as particular or specialist knowledge.

Social work, along with most other areas of health and social care practice, relies heavily on the use of verbal communication in its construction of relationships, development of a therapeutic alliance and achievement of key processes such as assessment. The extent of our reliance on verbal communication is illustrated by the fact that we may feel discomfited and vulnerable when faced with communicating with a person with dementia who does not use words, or communicates in unexpected ways or ways that 'break the rules' (see, for example, Killick and Allan, 2001).

Traditionally then, people with dementia have been perceived as people who, as they become progressively 'engulfed' by the condition, inevitably lose the ability to communicate. A perceived loss of communication ability is then linked to loss of personhood, which in turn fuels paternalistic practice, where communication with carers and family members becomes *about*, rather than *with* the person with dementia, especially where, for example, social workers want to undertake an assessment or discuss possible care options (Brooker, 2004). One implication of such an approach to communication is that it privileges the voice of carers over the voice of the individual with dementia. Decisions can be made 'for' and 'about' a person with dementia because they are effectively silenced, both as individuals and collectively.

The importance of communication, and seeking different and appropriate ways to communicate, have become even more fundamental to good practice in England and Wales since the Mental Capacity Act (2005) came into force in April, 2007. In Scotland, mental capacity is addressed in the Adults with Incapacity (Scotland) Act, 2000, but there is no equivalent law on mental capacity in Northern Ireland at the time of writing. The principles of the Mental Capacity Act include the presumption that adults have capacity unless it is established that they lack capacity; and, moreover, that all practical steps must be taken to help the person make decisions (McDonald and Taylor, 2006). Consequently, critical gerontological social work practice would seek to wholeheartedly embrace the importance of utilizing and developing communication skills which ensure that people with dementia have continued opportunities for social engagement, participation and inclusion.

The basic principles of empathy, warmth and genuineness (Truax and Carkhuff, 1967) remain fundamentally important skills for effective communication. But, beyond that, communicating positively with people with dementia often requires a shift in emphasis away from traditional patterns of (verbal) communication and its associated rules, towards developing greater self awareness of, for example, our use of non-verbal communication (Killick and Allan, 2001). The principle of congruence must underpin communication if it is to be effective. That is, 'what we believe must match what we say (verbally) which must match what we do with our body and voice. Any discrepancy will engender a mixed message and mixed messages serve only to confuse and threaten' (Perrin and May, 2000, p. 88). For example, it would be difficult to believe that someone was listening to us if they persistently glanced around the room, checked their watch and fidgeted with their diary.

Research suggests that skills in non-verbal communication in people with dementia are comparable to those of people who are not known to have dementia. Killick and Allan (2001) have argued that people with dementia may in fact have a greater enhancement of non-verbal skills because of the need to assess peoples' moods and disposition towards offering help or assistance. Communicating with a person with dementia may mean that we use physical contact (such as appropriate touch) along with eye contact, a smile and voice tone to communicate interest and engagement. We may use physical gestures to emphasize a verbal message, or perhaps use a photograph or picture to communicate. For a person with severe dementia, singing, massage, mirroring body movements and hand holding may all help to communicate engagement and presence (for a full discussion, see Killick and Allan, 2001). It is not possible to be prescriptive about the

best ways to use non-verbal communication, because what works with one person may not work well with another. Cultural factors, gender, personal preferences and the nature of the relationship will all influence ways in which communication develops and highlights the importance of thinking about interaction on the basis of the individual person, rather than trying to apply a 'blanket rule'. Consider, for example, the recent advancements in the use of Talking Mats™, described in Box 4.1.

Box 4.1 Research into practice: the use of Talking Mats™ in communicating with older people with communication difficulties

The use of Talking Mats™ has been assessed as a means of enhancing communication with older people with communication difficulties, living in a care home (Murphy et al., 2005). Ten older people participated in the research, all of whom had communication difficulties as a result of dementia, stroke or other long-term illness. Talking Mats™ provide pictorial representations of everyday topics (for example, activities). The research project worked with older people to establish their views about topics such as activities in the care home and the environment. The researchers concluded that the Talking Mats™ enhanced the participants' ability to communicate, helped them to organize and express what they wanted to say and increased motivation to participate in communication. The researchers concluded that Talking Mats™ had a variety of applications (for example, for use with people with comprehension difficulties, hearing loss, unclear speech, people without speech). The mats could provide an important part of a repertoire of communication skills to enable people to participate in research, evaluate services and communicate individual wishes, preferences, likes and dislikes.

Person-centred communication of the kind described in Box 4.1 means that practitioners need also to be aware of their own communication styles, the ways in which social work shapes and constructs their language, and to reflect on their use of non-verbal communication (Perrin and May, 2000). For example, an emphasis on open-ended questions typically used as good practice to elicit fuller responses may be difficult to cope with by a person with a poor working memory. Again, it is vital to consider how such practices may be experienced from the perspective of the individual with dementia rather than on the basis of a set of prescribed communication 'rules'. However, Box 4.2 illustrates some general and encompassing principles of person-centred communication practices which

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Box 4.2 Research into practice: relationship-centred approaches

Relationship-centred practice seeks to highlight the importance of interdependences and the reciprocal nature of close personal relationships. Adams and Gardiner (2005) highlight that relationship-centred practice moves beyond Kitwood's conception of 'malignant social psychology', which focused essentially on the subjective experience of a person with dementia. From a social constructionist perspective, the impact of structural factors such as identity, power, role and social location construct different sets of meaning within dementia care triads (Adams and Gardiner, 2005, p. 188). Other writers have commented on the likelihood of triadic interaction between social work or health care professionals, the person with dementia and their caregiver or supporter (for example, Biggs, 1993). Communication in triads can often create alliances that may effectively exclude one person from the encounter. People with dementia may be particularly susceptible to exclusion or marginalization in an encounter between a professional worker and care giver. On this basis, the authors identify the conditions for 'enabling dementia communication and disabling dementia communication', as highlighted below.

Enabling dementia communication	*Disabling dementia communication*
Removing unwanted stimuli	Interrupting
Getting in the right position	Speaking on behalf of the person with dementia
Promoting equal participation	Reinterpreting what the person with dementia was saying which undermines the credibility of accounts given by the person with dementia
Demonstrating (modelling) inclusive and enabling communication to the care giver and person with dementia	Using technical or professional language and jargon
Providing opportunities (and time) to talk and communicate	Talking out of earshot of the person with dementia (for example, on the way out to the front door)
Being sensitive to non-verbal cues	Taking sides by verbal utterances or non-verbal behaviour (e.g. body positioning, proximity)
Valuing and respecting the contributions of people with dementia	Ignoring the person and making no effort to communicate or include the person with dementia
Developing appropriate strategies to overcome communication difficulties	Ridicule
Promoting and encouraging joint decision-making	Not inviting the person with dementia to meetings or discussions that are about them

are important aide-memoires for gerontological social work practitioners (adapted from Adams and Gardiner, 2005).

Importantly too, it may take time for you as a practitioner to build up a relationship with a person who struggles to remember who you are, and may feel afraid or suspicious of you. It is likely that the interaction will need to be slowed down to maximize the opportunity for a person with dementia to participate and not be outpaced. For example, it may take time for a person to answer a question or formulate a response; deciding too quickly that a person cannot or will not respond may, in effect, stymie every attempt the person makes to communicate (Innes and Capstick, 2001). Like all of us, a person with dementia may also be better able to participate at some times of the day than others, while sensory issues such as acquired hearing loss are woefully neglected as a factor inhibiting communication with a person with dementia (Allen *et al.*, 2003), as are other physical conditions that might be painful and debilitating.

Assessment and care planning

Communication is clearly important when it comes to assessment and care planning for people with dementia. Yet critical questions remain about how social work practitioners communicate the purpose of assessment and, indeed, undertake an assessment with a person with memory impairment and communication difficulties. While, in our view, the kind of biographical approach discussed earlier clearly constitutes good practice where comprehensive, and indeed specialist, assessment is concerned, there are often tensions between what may constitute sound and inclusive practice, and the pressures created by the requirement for a speedy turnover of assessments (Gorman and Postle, 2003); an over-reliance on check lists that focus on medical models; and performance indicators that require assessments to begin within 48 hours of initial contact and for 70 per cent to be completed within two weeks, and the remaining 30 per cent within four weeks (McDonald and Taylor, 2006).

Care planning is also a vital component in the provision of services and support, and the link between the person's assessment and statement of need and the subsequent care plan should be clear. Of course, care plans do not just address the needs of the individual person with dementia; they also identify goals for the provision of support or services to carers or the wider family/support system. Like assessment, care plans should make use of biographical understandings as a way of assisting gerontological social workers

to deliver personalized and sensitive care and support. Most importantly, care plans should also make visible the involvement and participation of the people for whom they are intended; identify the outcomes that will be achieved by specific interventions; what steps will be taken or services/resources used to achieve outcomes; who will undertake different aspects of the intervention; and what needs to happen for the goal to be successful. They should also be physically accessible and, in keeping with the aspiration of improved communication, should be written in clear, jargon-free language and available in different formats if required (such as audio tape). People with dementia do not just (or indeed always) have physical care needs, and care plans should reflect this.

In addition, people with dementia may experience rapid change and transition, and Tibbs (2001) makes the point that care plans often need frequent adjustment if they are to remain meaningful to the experience of the person. The importance of continuity in the person leading care planning is crucial: it is problematic trying to adjust a care plan when a practitioner is new to the situation and has little insight into the changes that have taken place, or the baseline from which change has happened. This, of course, raises further issues for social workers who may find themselves organized into teams with discrete activities such as 'intake and assessment', 'complex care' and 'review and monitoring' teams. While this may address the organizational difficulty of practitioners holding large numbers of 'cases', it detracts from the possibility of people with dementia experiencing continuity by, for example, having the same gerontological social worker over a period of time.

Working with informal carers

Although we address the difficult issues practitioners face in working with informal carers later in the book (see Chapter 7), it is important to highlight here some of the ways that gerontological social workers can support the carers of people with dementia. First, in relation to assessment and care planning, it is evident that social workers are very well placed to provide a valuable source of support, assistance and advice to carers during the whole process. Provided they have taken the time to build sound relationships with the person with dementia and his or her carers, gerontological social workers will be able to address the concerns and worries of families in appropriate and supportive ways. Second, and of particular importance, gerontological social workers should be able to identify specific needs of carers in the process of assessment, and enable the carers to access appropriate support and resources to meet their own

needs. Third, they may participate in group support/education for carers (and potentially, individuals with dementia); and fourth, they can be instrumental in finding ways of encouraging those carers who wish to participate in the active care and support of people with dementia.

One practical example of this latter point is the potential afforded by life-story work. Life-story work has been identified as an important element in ensuring that individual biography is made visible by helping people to recall and record their personal history (Gibson, 1994). Gerontological social workers may contribute positively to this by, for example, helping a person with dementia and his or her family members/informal carers to begin a life-story book. Bell and Troxel (2001) highlight a number of significant ways in which life-story work may be used positively to enhance well-being:

- It is helpful in acting as a remembrance book for people with memory difficulties.
- Relationships between family members and a person with dementia can become unsettled or altered as a result of the declining cognitive powers of the person with dementia. Helping a person with dementia can be a very positive way of finding new ways of engaging with the person – providing a new source of interest and a positive relationship experience.
- It provides a framework to which people can refer when experiencing some form of transition, such as receiving new care or support at home, or moving to a residential setting.
- A life-story book can provide a source of communication; validate and celebrate achievements; keep the person at the centre of their own lives; and help with the development of new relationships.

As an illustration, Extract 4.4 highlights an important aspect of Grandma McKay's identity and her biography. How would you capture this information in life-story work? How could you try to ensure that these important parts of her life are identified as strengths and maintained as continuities?

In working with informal carers, we recognize the complexity and difficulties of these tasks and acknowledge that gerontological social workers have a fine line to tread between addressing and meeting the needs of the person with dementia, and ensuring that the needs of informal carers are also given adequate consideration. As we discussed in Chapter 2, access to services is often linked to diagnosis and to eligibility criteria and, as a result, one (unintended) consequence has been that carers who lack practical and emotional support and assistance have often come to the attention of formal services when

Extract 4.4 *Life-story work and identity*

Adrian looks how Grandma thinks real men should look. Grandma is appallingly sexist. Men should be tall, men should be broad, men should be strong. If I ask her why, she says feeble things like 'for working' ...

Adrian slobbily asks Grandma if she would like a cup of tea ... yes she would like some fresh. Adrian makes it with the maximum of fuss. Then he says he had better go and rest before the next shift. Grandma says he's done well and he's a fine worker and to get his head down at once and she'll wake him for his dinner. Very slowly, when he's gone, she gets up and lifts the pan of water into which she has mistakenly put the potato scrapings. She carries it carefully to the sink while Mum and I watch. Slowly she puts it down, accurately, on the draining board and then starts searching. Neither of us ask what she is looking for. We know she wouldn't be able to tell us. It becomes quite fascinating watching as drawer after drawer is opened, cupboard after cupboard inspected. She is in a trance. Probably she's already forgotten what she was looking for, but no. She locates a sieve. That's it. Back she goes to the sink and strains the potato scrapings through the sieve then lifts the pan onto the cooker. She sighs with contentment and tells us the soup will not be long, it'll be ready when the men come in.

(Margaret Forster, *Have the Men Had Enough?*)
Seen from Hannah's perspective, pp. 39–40.

effectively it is too late. A carer who becomes exhausted and over-burdened to the point that the person with dementia is then admitted to a care home, is an all too familiar tale. Moreover, the long-term consequences for the emotional health of informal carers involved in these kinds of circumstances remains relatively invisible and under-researched. This situation persists despite the fact that legislation now (theoretically) ensures that people who either do provide regular and substantial care, or who plan to provide regular and substantial care, are entitled to an assessment in their own right (Carers [Recognition and Services] Act, 1995; Carers and Disabled Children Act, 2000; Carers (Equal Opportunities) Act, 2004). Furthermore, the NICE/SCIE (2006) good practice guidelines in dementia care also emphasize the support needs of carers (see Box 4.3).

Box 4.3 Research into practice: NICE/SCIE clinical guidelines on supporting people with dementia and their carers (2006)

Evidence from research about interventions and services for carers was reviewed systematically. Evidence reviews highlighted:

- Misperceptions and misunderstandings by carers about dementia and its potential implications.
- A lack of supportive and proactive services directed at carers of people with dementia.
- The potential for information and knowledge to decrease the risk of depression in carers of people with dementia.
- The difficulties for carers from black and minority ethnic groups to access help and information.

Interventions involving training of carers and stress management which involved the person with dementia appeared to have the largest effect on carers' psychological health and well-being (Brodaty *et al.*, 2003).

Recommendations for carers of people with dementia included:

Care plans should include tailored interventions for carers of people with dementia, which should consider:

- Individual and group psycho-education.
- Peer support groups.
- Other forms of indirect support (e.g. telephone/internet).
- Training for carers about dementia, services and benefits.
- Involvement of other family members.
- The potential involvement of the person with dementia.
- Provision of transport, respite care and short breaks to enable carers to participation in such interventions.
- Specialist therapeutic support for carers experiencing psychological distress.

Conclusion

Since the early 1990s, the developing managerialist agenda has emphasized progressively the importance of managing effectively within finite resources, with a narrow focus on eligibility criteria. Increasingly, the assessment of risk and risk management has been utilized as a means of managing finite resources (see Chapter 3). As a consequence, people with dementia and their carers all too often come to the attention of social workers and health care workers only in a crisis, having already coped with the experience of dementia and

its implications and consequences for a considerable period of time. While there is evidence of the benefits of preventative, small-scale interventions having a positive impact on the quality of life of older people (Tanner, 2001), the ability of social services and health care departments to provide comprehensive and integrated preventative services remains largely aspirational. A critical approach, underpinned by the values, skills and knowledge we have discussed above, would assist practitioners and formal services to recognize the importance of early intervention and respond to people with dementia and their carers in more sensitive and effective ways. However, how agencies geared to eligibility criteria that define those 'most in need' can respond to such a development remains open to question (CSCI, 2006a).

stop and think

- What support services and resources are available in your area for older people recently diagnosed with dementia?
- How can practitioners support and assist people with dementia to actively participate in decisions about their support, care and housing needs?
- How can you find ways of keeping abreast of the research and developing knowledge about dementia?
- What are the potential benefits of life-story work for people with dementia?
- Are there any risks or difficulties that you would need to be aware of?

taking it further

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