Communication Empowerment Framework: An integrative framework to support effective communication and interaction between carers and people living with dementia

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**Abstract** 

**Objectives:** To demonstrate the utility of integrating three theoretical perspectives

(Mentalization Theory, Perceptual Control Theory and the Communicative Impact model),

which jointly illuminate the communication challenges and opportunities faced by family

care partners of people with dementia. To point the way to how this framework informs the

design and delivery of carer communication and interaction training.

**Method:** Conceptual synthesis based on a narrative review of relevant literature,

supported by examples of family care partners.

**Results:** We use the conceptual models to show how the capacity to mentalize ('holding

mind in mind') offers a greater sense of control over internal and external conflicts, with the

result that they can be deescalated in pursuit of mutual goals.

**Conclusions:** The integrative conceptual framework presented here highlights specific

psychological and relational mechanisms that can be targeted through carer training to

enhance communication with a person living with dementia.

Key words: Mentalization; Control Theory; communication; dementia; carer

Short title: Integrative communication framework: carers and people living with

dementia

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#### Introduction

In their recent systematic review of communication training-interventions for carers of people living with dementia, Morris, Horne, McEvoy & Williamson (2017) found that it is possible to improve carers' knowledge of communication strategies and skills. However, only a minority of the reviewed studies found improvements in the wellbeing of carers or people living with dementia. Knowing *that* certain interventions are effective in improving knowledge and skills does not always translate to knowing *how* to improve wellbeing. One reason for this may be the absence, or limited efficacy, of theoretical models underpinning training interventions. Even where a training approach is effective for knowledge and skills development, the lack of adequate underpinning theory can prevent an understanding of the mechanisms through which beneficial effects are realised (Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Popay et al., 2006). Consequently, it will be difficult to identify and justify potential routes towards improvements in training-interventions, and also to distinguish in a principled way between which input is actually enhancing specific communication and interactive abilities, rather than only building general knowledge of potential strategies.

Where detailed conceptual models are presented (e.g. Haberstroh, Neumeyer, Krause, Franzmann, & Pantel, 2011), the primary skills-related focus tends to be quite narrow and cognitively superficial; for example, advice on eliminating distractions and delivering limited content information in short, simple sentences. While such strategies will certainly be helpful, they do not encompass important considerations that affect interactive success, such as the dynamics of relationships and the capacity to understand and accommodate the other person's perspective. A recent systematic review indicated that in order to support carers with behaviour that challenges emotional support for carers' negative feelings and unmet psychological needs is important and could help maintain relational connections (Feast et al., 2016).

One of the most prevalent conceptual frameworks underpinning training-interventions is person-centred care (Morris et al., 2017; Eggenberger, Heimerl, & Bennett, 2013). But even such approaches (Kitwood, 1997; Mitchell & Agnelli, 2015) could be considered limited if their vital emphasis upon treating people living with dementia as individuals with purpose and meaning is insufficiently underpinned by an understanding of what is required to achieve this aim (Brooker, 2003; Higgs & Gilleard, 2016). Additionally, person-centred theories have primarily been developed for professional rather than family care relationships (e.g. Brooker, 2003; McCormack & McCance, 2006) and thus do not accommodate the additional relational and emotional dynamics of the latter. They have been criticised as not taking into account the degree of "interdependencies and reciprocities" (Nolan, Ryan, Enderby, & Reid, 2002, p. 203), which are particularly nuanced in family relationships (Smebye & Kirkevold, 2013), and for positioning people living with dementia as passive recipients of care instead of active agents (Bartlett & O'Connor, 2007; Smebye & Kirkevold, 2013).

[Table 1 near here]

The development of effective communication training-interventions requires a conceptualization of how interaction fits into the emotional and cognitive landscape.

Associated guidance for carers on how to navigate and change this landscape should be beneficial in helping them to improve the quality of their communication experience. This article maps the broader context of interaction, by demonstrating the main determinants of communication breakdown or challenge, and how they might be addressed in practice. Three existing models are integrated: **Mentalization** theory (Fonagy, 1991; Fonagy & Target, 1997), Perceptual Control Theory (PCT) (Powers, 1973) and the Communicative Impact model (Wray, 2016). All three have in common the reciprocity of effective engagement with others. That is, notwithstanding the likelihood that dementia carers will have to take more of

the strain than those they care for in improving communication, effective change will not be unidirectional. At the very least, rather than only changing their own communication choices, carers are required to create the conditions under which the person with dementia also has different choices in interaction. The reason for this is that communication occurs at the interface of both parties' agendas, and is shaped by their respective goals and perceptions (Moyle, 2010; Steeman, Casterlé, Dierckx, Godderis, & Grypdonck, 2006). Although the carer's perspective is the necessary focus for the development of carer training, the aim is to foster communication that enables both parties to be more in control of how interactions transpire.

The integrated framework outlined in this paper (Communication Empowerment Framework) has been developed to inform a communication and interaction training-intervention known as Empowered Conversations (Six Degrees Social Enterprise 2018), which is described in detail in a separate article. This framework emphasizes the importance of care partners trying to understand the perspective of the person they are caring for and indicates ways in which perspective-taking can be impaired. It demonstrates how carers can develop this understanding without losing sight of their own goals and responses. The framework indicates how communication can break down and ways in which it can be enhanced to support connected relationships. It specifies how conflicts can arise and indicates how they can be addressed. In this paper, challenges to communication and interaction are first detailed. Then the three theoretical models that inform the framework are described and finally the Communication Empowerment Framework is specified.

Key conceptual terms, marked in bold in the text, are defined in Table 1.

Seven challenges for communication and interaction in the dementia context

Several factors potentially contribute to difficulties in communication between family carers and people living with dementia, and it is these factors that need to be accommodated and explained in the conceptual modelling that follows.

- 1) Understanding change: Carers can have difficulties understanding the changing internal world of a person living with dementia. As cognition is compromised, it can impact not only on memory capacity, but also personality and, directly or indirectly, the content and manner of a person's communication (Pozzebon, Douglas, & Ames, 2016). Meanwhile, the person living with dementia is also trying to navigate these changes and may attribute them to others, and the environment. This in turn complicates the carer's task in trying to sustain stability in the relationship and in everyday activities.
- 2) Language: Dementia often causes changes in the production and comprehension of language (Bayles & Tomoeda, 2014; Obler & De Santi, 2000; Watson, Aizawa, Savundranayagam, & Orange, 2012; Wray, 2016). Carers may have difficulty understanding a person living with dementia, as their diminishing linguistic resources impede or reduce expression, or lead to unconventional solutions for getting meaning across (Pozzebon et al., 2016; Wray, 2016). Breakdowns in communication can result in either the person living with dementia or the carer getting frustrated, bored or tired about not being able to communicate as they would like; for example, when the carer needs to repeat things many times, or the person with dementia repeats the same anecdotes.
- 3) Theory of mind: There is evidence that some people living with dementia experience difficulties with theory of mind, i.e. inferring others' mental states on the basis of immediately available information (e.g. facial expression or tone of voice) (Bora, Eryavuz, Kayahan, Sungu, & Veznedaroglu, 2006; Bora, Walterfang, & Velakoulis, 2015; Heitz et al., 2016). This can put strain on the relationship with a carer, who may feel underappreciated and unheeded.

- 4) Role changes and interpersonal dependence: Increased dependence, along with cultural expectations, typically result in changes in the roles and relationship dynamics between a person living with dementia and a family carer (Butcher, Holkup, & Buckwalter, 2001; Russell, 2001). In turn, relationship changes may lead to departures from pre-existing communicative and interaction patterns. For example, a spouse or child may feel increasingly cast in a parent role (Pozzebon et al., 2016). During this transition, there may be considerable uncertainty about how to respond appropriately in certain situations (Polk, 2005; Wray, 2014)
- 5) Grief: Carers may also be experiencing a complex grief response (Butcher et al., 2001) as they observe the ongoing changes that the person living with dementia is undergoing, and experience their own emotional and social responses associated with the 'loss' of the person to the disease (Pozzebon et al., 2016). People have varying capacity for 'adaptive coping': the assimilation and acceptance of this change that will enable "restoration of coherence to the narrative of [their] lives" (Schut & Stroebe, 1999, p. 202).
- 6) Practical pressures, fatigue and social isolation: For many carers, the sheer quantity of hours during which they are responsible for a person living with dementia, which may extend to 24-7, make it all but impossible to get the emotional and physical distance needed for reflecting on how they are responding during interaction (Wray, 2016). Social encounters are often much reduced, and it can be difficult for some carers to seek support, if they fear stigmatization, or that others will not understand the nature and extent of their challenges (Pozzebon et al., 2016).
- 7) Attachment: Close family carers have significant 'attachment relationships' with those that they are caring for (see section 3.1). Interactions may be emotionally intense, often with unspoken and unrecognized tensions and expectations arising from the long history of the relationship (Pozzebon et al., 2016). These factors and the emotional significance of such

relationships can make it more difficult to maintain the cognitive distance needed for a considered response.

# **Overall conceptualization**

The framework that is proposed here draws together aspects of three theoretical accounts of how human beings negotiate their world and maintain psychological wellbeing.

Mentalization Theory relates to our perceptions about ourselves and others. Perceptual Control Theory concerns the ways in which **conflict** between our intrapersonal and interpersonal goals can impact on our external relationships. The conflict element of the Communicative Impact model addresses our internal and external responses to tensions arising (a) within our inner world, (b) in our external relations and (c) at the interface of the two. The theories are briefly outlined below, each being integrated with the one before, to develop a composite account that can shed more light on the deeper intricacies of dementia communication.

The intention is to present general principles without being positivistic. Every person is different and so is every interactional event. There are many cultural differences too, that shape communicative episodes. For example, in westernized culture, dementia is generally viewed as a medical condition caused by disease, but in some cultures dementia is considered a mental illness or a normal part of aging (Hinton, Franz, Yeo, & Levkoff, 2005; Narayan et al., 2015). There is also substantial evidence that the experience of being a family carer differs significantly across cultural groups (Napoles, Chadiha, Eversley, & Moreno-John, 2010). In ethnic minority groups subcultures can develop that contradict the dominant narratives of diagnosis and care (Cohen, 1998; Ikels, 1998; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; McLean, 2007). Therefore, culture can have an important, varied and complex

impact on carer experience. The framework we propose is not intended to undermine specific religious frameworks or cultural norms, or treat carers or people with dementia as one homogenous group. While it does assume that people with dementia experience cognitive and perceptual changes that are not a normal part of aging, it is shaped to inform techniques and training-interventions that can be used creatively to explore the meaning and implications of individuals' religious and cultural frameworks.

#### Mentalization

Mentalization is "the imaginative mental activity that enables us to perceive and interpret human behaviour in terms of intentional mental states (e.g., needs, desires, feelings, beliefs, and goals...)" (Fonagy & Luyten, 2009, p. 1357). This "holding the mind in mind" (Allen, Fonagy & Bateman, 2008, p. 3) begins with ourselves, but needs to extend to imagining the mental states of others. We do not have direct access to others' mental states, so we are reliant on various indirect points of access. One is our experience of our own mental states. We are likely to make associations with states and behaviours that we have experienced ourselves. For example, if someone looks tearful, we may infer likely thoughts contributing to this emotional response with reference to what we think would lead us to a similar response, e.g. someone has just said something unkind, or an event has put them in mind of something sad. However, our own mental states are not always a reliable point of reference, for at least two reasons. Firstly, we do not necessarily understand *ourselves* very well, and therefore are compromised in making inferences about others (Allen, Fonagy, & Bateman, 2008). Secondly, we may have complex and inaccurate beliefs about the connections between our own mental states and external factors, built up over many years; these may then influence how we interpret the nature of, and reasons for, others' states of mind.

A second point of access is our pre-existing models of the mind of the particular individual, based on knowing them for a long time, and experiencing them from our own (previous) role perspective. As roles, situations and personalities change in the course of dementia, it will become difficult to fully sustain these models, and attempting to do so may eclipse the cues indicating what the other person is actually communicating. If emotions are high, a carer will likely find it hard to slow their thinking down to evaluate the best approach in communication and care. This is because "mentalizing goes offline in the context of intense emotional arousal as the fight-or-flight response comes online" (Allen, Fonagy & Bateman, 2008, p. 133-134). At times of intense emotional arousal, patterns of brain functioning and responding can become more automatic and instinctive (Arnsten, Mathew, Ubriani, Taylor, & Li, 1999; Mayes, 2000). The threshold for switching from a mentalizing and flexible response to a more automatic response will vary between individuals (Mayes, 2000).

Consequently, it will be easier for a carer to work with the seven challenges for communication (section 2) if he or she has capacity for 'good mentalizing': an accurate and effective understanding of (a) his or her personally important goals; and (b) the other person's perspective that takes into account what is really important to them. As we shall see later, goals, rather than externalized behaviours, are crucial to understanding the dynamics of communication, and they are key to how mentalizing occurs. Research suggests that carers' attempts to mentalize are worth the effort. A recent analysis of video data from nine people living with dementia highlighted that even when the carer could not understand the message that was being communicated, attempts to understand and empathize were appreciated (Alsawy, Tai, McEvoy, & Mansell, 2017).

A key influence on mentalization theory is attachment theory, according to which infants are biologically predisposed to form attachments to those who (to a greater or lesser extent)

protect, soothe and look after them (Ainsworth, 1978; Ainsworth, Blehar, Waters, & Wall, 1978). Bowlby (1982) proposes that from such interactions with caregivers, individuals develop a mental representation of the self in relation to others, along with expectations about they should behave, and how others will behave, in social relationships. These constitute an important default for mentalizing, and thus, internal representations of attachment relationships influence interactions in adults across a range of contexts (Gleeson & Fitzgerald, 2014; Korver-Nieberg, Berry, Meijer, & Haan, 2014; Robles & Kane, 2014).

Significant attachment relationships shape our sense of identity or self (Fonagy, 1999; Pittman, Keiley, Kerpelman, & Vaughn, 2011; Shaver, Mikulincer, Sahdra, & Gross, 2016). In dementia care, long-established attachment relationships are disturbed: the child becomes the carer of the parent, or the wife shifts from intimate partner to a carer role. The significant relational changes experienced may challenge carers' sense of their own identity (Butcher et al., 2001; Shaver & Mikulincer, 2007; Tuomola, Soon, Fisher, & Yap, 2016). Nolte et al. (2013) found that in young healthy adults, attachment-related stress interfered with the functioning of brain regions associated with mentalization more than other kinds of stress did. Thus, the loss of the ability to mentalize, mentioned above, may be particularly acute in family relationships, where the stress is commonly attachment-related.

An example of an attachment challenge that family carers may face is the conflict between wanting the person to be 'as they were', yet having to deal with them 'as they are', that is, with the cognitive, memory, communication and personality changes resulting from dementia: "Seeing the person they had known for so long, who still was physically the same person but in many other ways so different, was an incongruity that at times seemed unreal" (Butcher et al., 2001; p. 46). As noted in section 2, grief is a common response to caring for a person with dementia (Pozzebon et al., 2016). A recent study of family dementia carers found that the changes associated with dementia were often experienced as threats to

knowledge, personhood and closeness (Ennis, Tai, McEvoy, & Mansell, 2017). These constitute multiple potential losses, and a capacity for adaptive coping (Schut & Stroebe, 1999) is not guaranteed. Where adaptive coping is successful, the capacity to mentalize means that it will often manifest as a recalibration of the carer's assumptions and priorities, as in Box 1.

[Box 1 near here]

Certain detrimental 'modes' can result from inadequate mentalization. In 'psychic equivalence' mental states are experienced as external reality, e.g. because I feel angry, they intended to anger me (Allen et al., 2008, p. 25). In 'pretend' mode, the mental state becomes detached from external reality, so that extensive mentalizing is needed to rationalize the feelings, e.g. explaining away dementia symptoms rather than facing the facts about their cause (Allen et al., 2008, p. 249). In 'teleological' mode, mental states are externalized as actions, as with self-cutting to communicate emotional pain (Allen et al., 2008, p. 350). See Table 2 for more details of these mentalization modes.

[Table 2 near here]

### Perceptual Control Theory (PCT) and conflict

Where mentalization theory focuses on 'modelling minds', PCT relates more specifically to the goals of those involved in interactions and how the individual engages externally. The theory is based on the tenet that life, and thereby effective functioning, is a process of **control**. Control in this sense means the attempt to match one's experiences with internally specified goals or '**reference values**'. That is, there needs to be an alignment between one's

priorities and what happens in the world. Without it, or when the person attempts to sustain multiple goals that are incompatible, conflict will be experienced and, where the priorities are important ones, distress (Kelly, Mansell, & Wood, 2015). Problems with control are associated with reduced well-being and psychopathology (e.g. Chorpita & Barlow, 1998; Fitzsimons & Fuller, 2002; Gray, Ozer, & Rosenthal, 2017; Harrow, Hansford, & Astrachan-Fletcher, 2009), and control-related conflict has been identified in the experience of family carers of people living with dementia (Shim, Barroso, & Davis, 2012). From a PCT perspective, enduring conflict between people's valued goals is a primary cause of loss of control, which manifests as distress and unwanted psychological symptoms, such as stress, low-mood and irritation (Alsawy, Mansell, Carey, McEvoy, & Tai, 2014).

Goals are conceptualized in a hierarchy, with the higher-levels, often associated with longer term values, setting the reference values for lower-levels (Powers, 1973). For example, the higher-level goal 'be a good friend' sets the goal 'keep in regular contact', which could lead to actions such as texting friends, meeting regularly, etc. Higher-level references often represent longer-term goals and values. Enduring conflict between higher-level references significantly contributes to loss of control and distress, as higher-level references specify a range of lower-level references (Alsawy et al., 2014; Kelly, Mansell, & Wood, 2011; Kelly et al., 2015).

The theory recognizes that since complete influence over events is rarely possible, the way to sustain adequate control, and thus avoid conflict and distress, is to recognize and adjust or abandon goals that cannot be achieved (Brandtstädter, 2009; Morris, Mansell, & McEvoy, 2016; Powers, 1973). This change happens through a trial and error process termed *reorganization* (Powers, 1973). Full resolution of internal conflict requires **reorganization** at the source of the conflict: which can be experienced as a shift in one's priorities, having an insight, or having a change in perspective on a problem (Gianakis & Carey, 2008, 2011;

Higginson & Mansell, 2008). Since higher-level conflict is particularly likely to endure, and promote significant distress (Kelly et al., 2011, 2015), a recognition of higher-level conflicting goal(s) is generally required to regain control. In turn, increased **awareness** of internal goals is important for re-establishing perceived control and hence resilience (Dias et al., 2015; Harmell, Chattillion, Roepke, & Mausbach, 2011).

People living with dementia may have a decreased capacity to rethink their situation, calibrate their goals appropriately, and act to achieve them, with the result that they experience reduced control (Moyle, 2010; Steeman et al., 2006). This leaves them vulnerable to their circumstances, making it vital that carers are able to manage any resulting externalized conflict, as explored in the next section.

## **Conflict and reduced Communicative Impact**

Like PCT, Wray's Communicative Impact model (Wray, 2016) identifies the achievement of personal goals as central to sustaining a sense of control over one's life. Her model, however, specifically focuses on the role of communication in achieving these goals, and the 'communicative impact' that a person's interactive turns have in moulding their world as they want and need it to be. Much of the purpose of communication, in this view, is getting others to act as agents when it is not possible for the speaker to achieve change directly. Since people have multiple goals, communication is subtle. For example, a rude request to close a door may result in a closed door, but undermine the goal of sustaining a valued relationship. As a result, humans' linguistic and non-verbal choices in communication are carefully tailored to navigate maximising success on several fronts at once.

In dementia, communication is a significant casualty (Wray, 2018), with associated impact on the mental health of carers (Watson et al., 2012). The intricacies of effective

communication, easily disturbed by changes in language patterns and relationships, are further undermined by the conflicts arising from unmet goals, as laid out in PCT.

Interpersonal conflicts, such as arguments, expressions of frustration and anger, etc., can be conceptualized as external manifestations of internal conflict (Wray, 2016). Often, the failure to deploy communication effectively to achieve multiple, possibly contradictory, personal goals generates an emotional response (e.g. anger, stress or depression) that impedes effective mentalization.

Wray's model offers specific insights into the problems that can occur when communicating with a person living with dementia. One is a paradox that can arise between the desire to treat a person living with dementia as 'like me', where the person's behaviour as viewed as bounded by normal social conventions, versus re-mentalizing, to see the person as 'not like me', which accommodates any behaviour that would otherwise be upsetting or offensive (Wray, 2013). The latter option can protect the carer's emotional state by neutralising hurtful or annoying behaviours. However, distancing like this could draw the carer into dehumanising the person with dementia (Feast et al., 2016). Wray argues that if the high-level goal of being a good person conflicts with the high-level goal of self-protection through distancing, the carer may be trapped in guilt and anxiety, leading to extreme stress. Wray proposes that if we once we recognize how internal conflict can be the source of external conflict, "it becomes possible to identify options for resolving conflict, which are not available if conflict is located only in the external social space" (Wray, 2016, p. 117).

Box 2 is an example of how awareness of internal conflicted goals can result in constructive attempts to meet the goals of all involved in the interaction. It was recounted by a carer at one of our Empowered Conversation training courses and has been fully anonymised and adapted to protect identities.

[Box 2 near here]

# Towards supportive interventions in carer training: the Communication Empowerment Framework

Carers may face many challenges, but they are also capable of identifying the positive aspects of their role (Brodaty & Donkin, 2009). Furthermore, people living with dementia can draw on considerable resources of resilience (Desai, Desai, McFadden, & Grossberg, 2016). One method for supporting both carers and people living with dementia is training for carers. Research indicates that the acquisition of knowledge and skills can support carer resilience and the maintenance of positive relationships with those cared for (Donnellan, Bennett, & Soulsby, 2015); for example, understanding how memory changes influence communication can enable more accurate mentalization. In particular, communication-focused training interventions can enhance perceived coping and control (Dias et al., 2015; Eggenberger et al., 2013; Harmell et al., 2011).

Jointly, the theories and models reviewed above offer new insights into how this can be achieved. In the Communication Empowerment Framework, these theories are integrated; generating a means for emphasizing the importance of care partners trying to understand the perspective of the person they are caring for, while not losing sight of their own goals and experiences. This framework specifies how conflicts can arise and indicates how these can be addressed. It indicates other specific ways that communication can break down and be enhanced.

Training programmes need to provide techniques for responding to daily challenges that encourage the resolution of internal conflicts between higher-level goals, because this will increase the scope for control and thus promote resilience (Alsawy et al., 2014; Dias et al., 2015; Harmell et al., 2011; Morris, Mansell, & McEvoy, 2016). As noted above, reorganizing

and resolving higher-level conflicts is also likely to improve communication, because it reduces the likelihood of external conflict. In turn, good relationships make it easier to spend time together and share activities, which people living with dementia identify as important to them (Alsawy et al., 2017). Carers benefit through the fulfilment of higher-level goals like creating joy and supporting the person living with dementia, someone they have loved and known for a significant amount of time (Butcher et al., 2001; Russell, 2001). Raising awareness of higher-level goals thus exposes not only self-oriented priorities but also other-oriented ones, enabling a creative approach to working with conflicting goals (Morris, Mansell, & McEvoy, 2016).

Carers learn that even when an interaction features elements of conflict, such as disagreement or verbal aggression, shared cooperative goals may underpin it. For example, it is likely that both parties want to achieve lower-level goals (e.g. the successful eating of a meal) alongside higher-level ones (e.g. sustaining calm and good humour). Drawing carers' attention to the probability that any external conflict is not born of contradictory goals but of different, perhaps misleading, ways of achieving aligned goals can be enough to help the carer re-mentalize the situation to exploit the underlying harmony in their intentions. Thus, even if there is conflict at one level of the **control system**, identifying collaborative goals can stop conflict escalating (Morris et al., 2016; McClelland, personal communication). Box 3 gives an example.

[Box 3 near here]

A key focus of the framework provided is recognizing how communicative behaviours on the part of the carer can unintentionally undermine the experience of control in the person they are caring for. For example, if the carer is aggressive, or unable to achieve basic communicative goals because of an internal conflict, the person living with dementia will have a reduced range of options for responding. Since enduring goal conflicts are likely to cause distress and stress (Gray et al., 2017; Kelly et al., 2015), helping carers to work around them is crucial.

Carers need to be supported in effective mentalizing, taking into account the current situation and not remaining in thrall to historical goals that can no longer apply. Mentalizing involves an integrated response to self and other and takes into account all perceptual data reasonably accurately, including the present situation, the likely perspective of the other person, and their own goals and emotional responses. "Great effort is required to attend to and reflect on mental states, especially when striving to hold multiple perspectives in mind in the midst of strong emotions" (Allen et al., 2008, p. 70).

It is also important to reassure carers that the temporary loss of mentalization is normal, since our attention fluctuates with context and mood. Thus, it is not a matter of having to sustain a highly deliberated perspective all the time, but of recognizing the risks of prolonged and intense loss of mentalization for precious interpersonal relationships.

Ineffective mentalizing occurs when a particular mode (see section 3.1) is used rigidly and inflexibly (Lemma, Target, & Fonagy, 2011; Morris & Mansell, in press). For example, if frustration becomes all-consuming, then it is likely to become difficult not to link it to the external reality (psychic equivalence mode – see Table 2), such as believing that the person with dementia is being deliberately annoying. If the teleological mode is entered, the carer may act on the emotion, by showing physical or verbal aggression (Asen & Fonagy, 2017a, 2017b). Although acknowledging anger is the first step, carers can be helped to recognize how, when anger is the dominant state, mentalizing becomes difficult and it is easy to lose perspective. That is when people do things that they later regret, and cause estrangement from those around them (Asen & Fonagy, 2017a). Rigid use of mentalization modes becomes problematic and distressing when this blocks the more important higher-level goals that are

the truer reflection of the carer's core intentions, such as commitment and care (Morris & Mansell, in press).

#### Conclusion

We have shown how conflicts within and between people, with regard to their higher- and lower-level goals, are more or less inevitable, and that they are likely to result in emotional responses that shape the content and tone of communication. Since language is a window on our thoughts, it is very difficult fully to shield others from the emotive power behind our words and non-verbal signals. Carers of people living with dementia experience high levels of stress on account of their situation and the many conflicting goals they must deal with, including those that relate to their non-carer identities. They also often have a high level of commitment to maintaining connection with the person they are caring for.

Carers can be effectively supported by the opportunity to reflect on how these dynamics play out in their daily lives, and being helped to develop mentalization strategies that can give them the capacity to identify and then fulfil their own, and the others', goals. We have described challenges that can affect communication between carers and people living with dementia. Responding creatively to these challenges and building on strengths and resilience can lead to more satisfying communication. This paper details specific psychological and relational mechanisms that can be targeted to enhance communication; the Communication Empowerment Framework. This framework indicates (a) why it is important for both individuals in a conversation to feel that they have control, and (b) how the carer can be equipped to recognize intra- and interpersonal goal conflicts and resolve them. Key elements that facilitate the resolution of internal and external conflicts include being able to recognize and express concerns (even if not always directly to the person with dementia),

identify the source and nature of the conflict, engage with changes in emotion, and sustain an awareness of how thoughts and relationships are shifting.

For this reason, our training approach, Empowered Conversations, focuses on the above elements, as a way of helping carers develop enhanced mentalization and facilitate **cognitive flexibility** (Morris & Mansell, in press; Morris, Mansell, Amos, & Edge, 2016); a flexibility of awareness in relation to important goals that results in appropriate practical actions. Examples of methods to enhance these processes include being able to express and discuss concerns in order to elaborate mentalization of self and others; engaging with conflicts and changes in emotion enhances the ability to consider strong emotions and respond flexibly. Empowered Conversations also provides carers with techniques that will assist the person with dementia to connect with their goals and regain control. For example, carers are taught the 'invitation to respond' technique, which allows people living with dementia to respond if they want to. Details of the techniques used in Empowered Conversations are presented in our companion paper (in preparation) and on our website, <a href="http://empowered-conversations.co.uk/">http://empowered-conversations.co.uk/</a>.

In summary, the key features of the Communication Empowerment Framework enable it to generate direct practical implications. It supports care partners to 'hold in mind' both their goals and the likely goals of the person they are caring for. It specifies ways in which communication can be impaired and related ways it can be enhanced; these include attention to emotion and non-verbal communication and the impact each of these can have on communication. Further, it delineates ways in which carers can be supported to identify and meet the important goals of all those involved in an interaction.

#### References

- Ainsworth, M. D. (1978). The Bowlby-Ainsworth attachment theory. *Behavioral and brain sciences*, *1*(3), 436-438.
- Ainsworth, M. D., Blehar, M. C., Waters, E., & Wall, S. (1978). Patterns of attachment: Assessed in the strange situation and at home: Hillsdale, NJ: Erlbaum.
- Allen, J. G., Fonagy, P., & Bateman, A. W. (2008). *Mentalizing in clinical practice*. London, England: American Psychiatric Pub.
- Alsawy, S., Mansell, W., Carey, T. A., McEvoy, P., & Tai, S. J. (2014). Science and practice of transdiagnostic CBT: a Perceptual Control Theory (PCT) approach. *International Journal of Cognitive Therapy*, 7(4), 334-359.
- Alsawy, S., Tai, S., McEvoy, P., & Mansell, W. (2017). "It's nice to think somebody's listening to me instead of saying 'oh shut up'". People with dementia reflect on what makes communication good and meaningful. *Manuscript submitted for publication*.
- Arnsten, A., Mathew, R., Ubriani, R., Taylor, J., & Li, B. (1999). Alpha-1 noradrenergic receptor stimulation impairs prefrontal cortical cognitive function. *Biological psychiatry*, 45(1), 26.
- Asen, E., & Fonagy, P. (2017a). Mentalizing family violence part 1: Conceptual framework. *Family process*, 56(1), 6-21.
- Asen, E., & Fonagy, P. (2017b). Mentalizing family violence Part 2: Techniques and interventions. *Family Process*, *56*(1), 22-44.
- Bayles, K. A., & Tomoeda, C. K. (2014). *Cognitive-communication disorders of dementia* (2nd ed.). San Diego, CA: Plural Publishing.
- Bora, E., Eryavuz, A., Kayahan, B., Sungu, G., & Veznedaroglu, B. (2006). Social functioning, theory of mind and neurocognition in outpatients with schizophrenia; mental

- state decoding may be a better predictor of social functioning than mental state reasoning.

  Psychiatry research, 145(2), 95-103.
- Bora, E., Walterfang, M., & Velakoulis, D. (2015). Theory of mind in behavioural-variant frontotemporal dementia and Alzheimer's disease: a meta-analysis. *J Neurol Neurosurg Psychiatry*, 86(7), 714-719.
- Bowlby, J. (1982). Attachment and loss: Retrospect and prospect. *American journal of Orthopsychiatry*, 52(4), 664.
- Brandtstädter, J. (2009). Goal pursuit and goal adjustment: Self-regulation and intentional self-development in changing developmental contexts. *Advances in Life Course Research*, 14(1), 52-62.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues Clin Neurosci*, 11(2), 217-228.
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in clinical gerontology*, 13(3), 215-222.
- Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23(1), 33-55.
- Chorpita, B. F., & Barlow, D. H. (1998). The development of anxiety: the role of control in the early environment. *Psychological bulletin*, *124*(1), 3.
- Cohen, L. (1998). *No aging in India: Alzheimer's, the bad family, and other modern things*: Univ of California Press.
- Desai, A. K., Desai, F. G., McFadden, S., & Grossberg, G. (2016). Experiences and Perspectives of Persons with Dementia. In M. Boltz & J. E. Galvin (Eds.), *Dementia Care* (pp. 151-166): Springer

- Dias, R., Santos, R. L., Sousa, M. F. B. d., Nogueira, M. M. L., Torres, B., Belfort, T., &
  Dourado, M. C. N. (2015). Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends in psychiatry and psychotherapy*, 37(1), 12-19.
- Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & mental health*, 19(10), 932-939.
- Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345-358. doi: 10.1017/S1041610212001664
- Elvish, R., Lever, S.-J., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research*, 13(2), 106-125.
- Ennis, L., Tai, S., McEvoy, P., & Mansell, P. (2017). The phenomenology of good communication from the perspectives of family caregivers of people with dementia. *Manuscript in preparation*.
- Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016).

  Behavioural and psychological symptoms in dementia and the challenges for family carers:

  Systematic review. *The British Journal of Psychiatry*, 208(5), 429-434.
- Fitzsimons, S., & Fuller, R. (2002). Empowerment and its implications for clinical practice in mental health: A review. *Journal of Mental Health*, 11(5), 481-499.
- Fonagy, P. (1991). Thinking about thinking: Some clinical and theoretical considerations in the treatment of a borderline patient. *The International journal of psycho-analysis*, 72(4), 639.

- Fonagy, P. (1999). Attachment, the development of the self, and its pathology in personality disorders. *Treatment of personality disorders*, 53-68.
- Fonagy, P., & Luyten, P. (2009). A developmental, mentalization-based approach to the understanding and treatment of borderline personality disorder. *Development and psychopathology*, 21(4), 1355-1381.
- Fonagy, P., & Target, M. (1997). Attachment and reflective function: Their role in self-organization. *Development and psychopathology*, *9*(4), 679-700.
- Gianakis, M., & Carey, T. A. (2008). A review of the experience and explanation of psychological change. *Counselling Psychology Review*, 23(3), 27-38.
- Gianakis, M., & Carey, T. A. (2011). An interview study investigating experiences of psychological change without psychotherapy. *Psychology and Psychotherapy: Theory, Research and Practice*, 84(4), 442-457.
- Gleeson, G., & Fitzgerald, A. (2014). Exploring the association between adult attachment styles in romantic relationships, perceptions of parents from childhood and relationship satisfaction. *Health*, *6*(13), 1643.
- Gray, J. S., Ozer, D. J., & Rosenthal, R. (2017). Goal conflict and psychological well-being:

  A meta-analysis. *Journal of Research in Personality*, 66, 27-37.
- Haberstroh, J., Neumeyer, K., Krause, K., Franzmann, J., & Pantel, J. (2011). TANDEM:

  Communication training for informal caregivers of people with dementia. *Aging & Mental Health*, *15*(3), 405-413. doi: 10.1080/13607863.2010.536135
- Harmell, A. L., Chattillion, E. A., Roepke, S. K., & Mausbach, B. T. (2011). A review of the psychobiology of dementia caregiving: A focus on resilience factors. *Current psychiatry reports*, *13*(3), 219-224.

- Harrow, M., Hansford, B. G., & Astrachan-Fletcher, E. B. (2009). Locus of control: Relation to schizophrenia, to recovery, and to depression and psychosis—A 15-year longitudinal study. *Psychiatry research*, *168*(3), 186-192.
- Heitz, C., Noblet, V., Phillipps, C., Cretin, B., Vogt, N., Philippi, N., . . . Demuynck, C. (2016). Cognitive and affective theory of mind in dementia with Lewy bodies and Alzheimer's disease. *Alzheimer's research & therapy*, 8(1), 10.
- Higginson, S., & Mansell, W. (2008). What is the mechanism of psychological change? A qualitative analysis of six individuals who experienced personal change and recovery.

  Psychology and Psychotherapy: Theory, Research and Practice, 81(3), 309-328.
- Higgs, P., & Gilleard, C. (2016). Interrogating personhood and dementia. *Aging & mental health*, 20(8), 773-780.
- Hinton, L., Franz, C. E., Yeo, G., & Levkoff, S. E. (2005). Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society*, *53*(8), 1405-1410.
- Ikels, C. (1998). The experience of dementia in China. *Culture, Medicine and Psychiatry*, 22(3), 257-283.
- Kelly, R. E., Mansell, W., & Wood, A. M. (2011). Goal conflict and ambivalence interact to predict depression. *Personality and Individual Differences*, 50(4), 531-534.
- Kelly, R. E., Mansell, W., & Wood, A. M. (2015). Goal conflict and well-being: A review and hierarchical model of goal conflict, ambivalence, self-discrepancy and self-concordance. *Personality and Individual Differences*, 85, 212-229.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

- Korver-Nieberg, N., Berry, K., Meijer, C. J., & Haan, L. (2014). Adult attachment and psychotic phenomenology in clinical and non-clinical samples: A systematic review. *Psychology and Psychotherapy: theory, research and practice,* 87(2), 127-154.
- Lemma, A., Target, M., & Fonagy, P. (2011). *Brief dynamic interpersonal therapy: A clinician's guide*. Oxford, UK: Oxford University Press.
- Mahoney, D. F., Cloutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: cross-cultural similarities and differences. *The Gerontologist*, 45(6), 783-792.
- Mayes, L. C. (2000). A developmental perspective on the regulation of arousal states. Paper presented at the Seminars in perinatology.
- McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of advanced nursing*, *56*(5), 472-479.
- McEvoy, P., Eden, J., Morris, L., & Mansell, W. (2016). Dementia: towards a perceptual control theory perspective. *Quality in Ageing and Older Adults*, *17*(4), 229-238.
- McLean, A. (2007). The person in dementia: A study of nursing home care in the US: University of Toronto Press.
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, 30(7), 46-50.
- Morris, L., Horne, M., McEvoy, P., & Williamson, T. (2017). Communication training interventions for family and professional carers of people living with dementia: a systematic review of effectiveness, acceptability and conceptual basis. *Aging & mental health*, 1-18.
- Morris, L., & Mansell, W. (in press). A systematic review of the relationship between rigidity/flexibility and transdiagnostic cognitive and behavioral processes that maintain psychopathology. *Psychopathology Review*.

- Morris, L., Mansell, W., Amos, R., & Edge, D. (2016). Experiences of a transdiagnostic group, the Take Control Course, for clients with common mental health problems: a qualitative study. *Manuscript submitted for publication*.
- Morris, L., Mansell, W., & McEvoy, P. (2016). The take control course: Conceptual rationale for the development of a transdiagnostic group for common mental health problems.

  Frontiers in psychology, 7.
- Moyle, W. (2010). Is quality of life being compromised in people with dementia in long-term care? *International Journal of Older People Nursing*, *5*(3), 245-252.
- Napoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease & Other Dementias*®, 25(5), 389-406.
- Narayan, S. M., Varghese, M., Hepburn, K., Lewis, M., Paul, I., & Bhimani, R. (2015). Caregiving experiences of family members of persons with dementia in south India.

  American Journal of Alzheimer's Disease & Other Dementias®, 30(5), 508-516.
- Nolte, T., Bolling, D. Z., Hudac, C. M., Fonagy, P., Mayes, L., & Pelphrey, K. A. (2013).

  Brain mechanisms underlying the impact of attachment-related stress on social cognition.

  Frontiers in human neuroscience, 7.
- Obler, L. K., & De Santi, S. (2000). Eliciting language from patients with Alzheimer's disease. In L. Menn & N. B. Ratner (Eds.), *Methods for studying language production* (pp. 403-416). Mahwah, NJ: Lawrence Erlbaum Associates
- Pittman, J. F., Keiley, M. K., Kerpelman, J. L., & Vaughn, B. E. (2011). Attachment, identity, and intimacy: Parallels between Bowlby's and Erikson's paradigms. *Journal of Family Theory & Review*, *3*(1), 32-46.
- Polk, D. M. (2005). Communication and family caregiving for Alzheimer's dementia: Linking attributions and problematic integration. *Health communication*, 18(3), 257-27

- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., . . . Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*, b92.
- Powers, W. T. (1973). Behavior: The control of perception: Aldine Chicago.
- Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. *International psychogeriatrics*, 28(4), 537-556.
- Robles, T. F., & Kane, H. S. (2014). The attachment system and physiology in adulthood: Normative processes, individual differences, and implications for health. *Journal of personality*, 82(6), 515-527.
- Russell, R. (2001). In sickness and in health: A qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies*, 15(4), 351-367.
- Schut, M., & Stroebe, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death studies*, *23*(3), 197-224.
- Shaver, P. R., & Mikulincer, M. (2007). Adult attachment strategies and the regulation of emotion. In J. Gross (Ed.), *Handbook of emotion regulation* (Vol. 446-465). New York: Guilford Press
- Shaver, P. R., Mikulincer, M., Sahdra, B., & Gross, J. (2016). Attachment Security as a Foundation for Kindness Toward Self and Others. In B. K.W. & L. M. R. (Eds.), *The Oxford Handbook of Hypo-egoic Phenomena*. Oxford, UK: Oxford University Press
- Shim, B., Barroso, J., & Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences. *International journal of nursing studies*, 49(2), 220-229.

- Steeman, E., Casterlé, D., Dierckx, B., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal of advanced nursing*, 54(6), 722-738.
- Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *Journal of cross-cultural gerontology*, 31(2), 157-172.
- Watson, B., Aizawa, L. D., Savundranayagam, M. Y., & Orange, J. (2012). Links among communication, dementia and caregiver burden. *Canadian Journal of Speech-Language Pathology and Audiology*, *36*(4), 276-283.
- Wray, A. (2013). Mislaying Compassion: Linguistic Triggers of Inadequate Caregiving. In B.H. Davis & J. Guendouzi (Eds.), *Pragmatics in Dementia Discourse* (pp. 117-145).Newcastle-Upon-Tyne: Cambridge Scholars Publishing.
- Wray, A. (2014). Formulaic language and threat: the problem of empathy and compassion in Alzheimer's disease interaction. In R. T. Schrauf & N. Mueller (Eds.), *Dialogue and dementia: cognitive and communicative resources for engagement* (pp. 263-286). New York: Psychology Press
- Wray, A. (2016). Mechanisms of conflict and aggression in the dementia context. *Journal of Language Aggression and Conflict*, 4(1), 114-140.
- Wray, A. (2018). Dementia: the 'communication disease'. Youtube video.

Table 1. Glossary of key terms used.

Term	Definition	Example		
Mentalization	The activity of perceiving and interpreting	Realising that you are avoiding someone because you feel hurt by something		
	human behaviour in terms of mental states.	they have done. Seeing that someone's face is screwed up in a certain way and		
	Such mental states include emotions, needs and	inferring that they maybe angry.		
	goals.			
Attachment	A significant relationship from which an	Spouse, long-term romantic partner, child, parent are all significant attachment		
relationship	individual is predisposed to seek support,	relationships. For example, a child is predisposed to seek care from a parental		
	protection and care. A relationship underpinned	figure, and this is the case even if there are difficulties within the relationship		
	by a strong emotional bond.	or the required care is not always forthcoming.		
Reference	Internal standards based on genetic	A good cup of coffee is milky but strong; being a good person means being		
values or goals	predisposition and/or past experience and	kind, caring etc.		
	encompassing values, beliefs, etc. A set of			
	personal 'just rights'.			
Control	Capacity to match a perception to a desired	Managing to be a supportive carer; Managing to keep feelings of stress at		
	reference value.	zero; Managing to live a good life.		

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Control system	Internal reference values that are arranged in a	The self-concept of being caring (higher-level goal) leads to the sub-goal of		
(hierarchical)	hierarchical network. Higher-level goals support	providing support when needed and, in turn, the lower-level, shorter-term goal		
	a range of lower-level ones.	of always being available if a loved one needs support.		
(Goal) conflict The state when two control systems attempt to Some care		Some carers can feel oppressed by not being able to manage their time as they		
	control an experience with respect to two (or	want. The goal 'I want to be able to control what I do' is in conflict with the		
	more) opposing reference values.	goal 'I want to be responsive and supportive at all times'.		
Reorganization	Changes arising from an awareness of conflict	A carer realizes that supporting the person living with dementia is more		
	between reference values. Trial-and-error	important than being in control of their own schedule. They realize that is		
	gradually results in reduction in the conflict. A	important to take breaks and look after themselves when possible and so		
	shift in perspective could indicate that	'soften' their goal of providing support 'at all times' to 'I'll do my best to be		
	reorganization has successfully occurred.	responsive and supportive'.		
Awareness	An index of the current focus; reorganization	A carer is able to pinpoint a source of conflict between goals that are		
	occurs at the focus of current awareness.	important to them and thus mentalize around it.		
Cognitive	A flexibility of awareness that involves a broad	Making time in various ways to respond to ill health in a loved one, by		
flexibility	awareness of higher-level (important) goals, and	modifying one's goals in line with an overall higher-level goal 'I want to		
	a mobility of awareness that enables these to be	support those I love'.		

implemented via flexible lower-level goals.

Table 2: Modes of experience when mentalization breaks down

Mode	Definition	Explanation	Example 1	Example 2
Psychic	"Mental representations	Psychic equivalence mode can be	A qualitative study of family	Understanding socially
equivalence	not distinguished from	characterised as "thoughts and	carers of people living with	unacceptable behaviour (e.g.
	the external reality that	feelings become 'too real' and	Alzheimer's dementia	loud voice and swearing) as a
	they represent" (Allen,	immovably 'true" (Allen et al.,	highlighted the commonality of	deliberate or calculated
	Fonagy, & Bateman,	2008, p. 25). It includes	attributions of anger to personal	behaviour, instead of a by-
	2008, p. 91).	attributing one's mental states to	attacks or deliberate attempt to	product of cognitive and
		others; for example, 'I feel	irritate (rather than forgetfulness	communication difficulties.
		rejected so they have rejected me'	cognitive/other changes) (Polk,	
		(Allen et al., 2008).	2005).	
Pretend	"Mental states are	Subjective thoughts and emotions	Common (and understandable)	'Pretend mode' could be used
	decoupled from reality	become completely separated	when people are waiting for a	to put painful emotions and
	yet, unlike in	from reality and mentalizing	diagnosis. In the absence of	thoughts to one side and carry
	mentalizing, not	becomes excessive but lacking in	having a sense of why	on as though things are how
	flexibly linked to	depth and genuine meaning. For	someone's memory and	

	reality" (Allen et al.,	carers, this could involve getting	perception is changing, it is easy	we want them to be
	2008, p. 249).	caught up in explanations of the	to get into elaborate- but	(McEvoy, 2018).
		motives and intentions person that	inaccurate- explanations.	
		they are caring for that have little		
		basis in reality.		
Teleological	"Mental states are	This refers to the assumption that	Task-focused rather than person-	Assuming that the other
	expressed in goal-	doing something can solve	centred care, where evidence of	person no longer cares about
	directed actions instead	emotional difficulties; for	'care' is what has been done	them if they are unable to
	of explicit mental	instance, anger can be resolved by	rather than our own and others'	express their care in words
	representation such as	violence or destruction of	mental states (McEvoy, 2018).	(this mode can demand very
	words; for example,	property.		physical and concrete
	when self-cutting is			expressions of support).
	employed as a way of			
	communicating			
	emotional pain" (Allen			
	et al., 2008, p. 350).			

# Box 1: An example of adaptive coping by a dementia carer

"Fred's spouse believed that they were not living in their real home that they had occupied since the early 1960s and wanted to be taken 'home, to the other place, it is so much nicer.' After months of frustration, Fred decided that he would, in his words, 'take charge' and formulated a plan in which they would 'go home, to the other place. His wife wanted to take certain items, so Fred phoned their daughter, who 'quickly caught on and went along with it,' to transport the items to 'the other place' while he and his spouse were in transit." (Russell 2001, p.362)

# **Box 2: Addressing conflicting goals**

When she visited her Mum, who had dementia, Claire sometimes ironed while watching TV. She did this because she felt she needed a break. But she was also aware that her Mum was distressed when she was ironing. Claire experienced both an internal conflict between wanting a break and not wanting her Mum to be distressed, and an external conflict, because of the way her Mum's distress manifested. Claire inferred that her Mum thought Claire was ignoring and excluding her. Through awareness of her internal conflicted goals, Claire was able to recognize that she was not fully meeting either of her goals fully: her Mum's distress meant she did was not really having a break. She realized that it would be more of a break for her if her Mum was involved in the ironing process, because then her Mum would not be distressed. So, she asked her Mum to pass her the clothes. Through identifying her internal goals (one of which directly referred to another person's goals) Claire was able to reach a positive compromise. If she has just focused on reducing her Mum's distress, she might not have arrived at this solution; for example, she might have only tried to calm and soothe her, instead of addressing the underlying conflict.

# **Box 3: The de-escalation of external conflict**

Elaine is getting increasingly irritable with Burt, whom she is caring for. She finds herself snapping at him. Even so, some elements of collaborative low-level collective control are still present, such as using a common language and orientating her body towards him (McClelland, personal communication). Suddenly, she realises that she is snapping and notices that he seems a bit withdrawn. She reflects that she does not want to upset him (her higher-level goal) and that she values their relationship (shared higher-level goal). It is likely that these higher-level goals are at the periphery of Elaine's awareness throughout the interaction, tempering her reactions. She probably also has a higher-level perception that physical violence is unacceptable (Wray, 2013), which contributes to her not being physically aggressive (McClelland, personal communication). Training can help carers like Elaine more quickly and easily to identify shared and collaborative goals, with a consequent reduction in external conflict (McEvoy, Eden, Morris, & Mansell, 2016).