

## Awareness in Alzheimer's disease and associated dementias: Theoretical framework and clinical implications

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**Background:** Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications, expressed explicitly or implicitly. Disturbances of awareness have significant implications for people with dementia and their caregivers. The construction of awareness has been extensively studied in dementia, but a lack of conceptual and methodological clarity in this area means that few clear findings have emerged.

**Aims:** This article presents a framework for conceptualizing awareness in people with Alzheimer's disease and associated dementias that can guide research and influence practice.

**Overview:** This article begins by considering the general concept of awareness and the ways in which neurological damage can place constraints on awareness. Within an integrative biopsychosocial model that acknowledges the influence of neurocognitive, psychological, and social variables on awareness, challenges for empirical research on awareness in dementia are addressed, and a 'levels of awareness' framework is presented within which awareness operates at four levels of increasing complexity, providing a means of differentiating among awareness phenomena. Approaches to mapping awareness phenomena are discussed, and directions for future research and clinical practice are outlined.

**Conclusions:** The levels of awareness framework should act as a stimulus to further research in this area, resulting in a more coherent understanding of the nature of awareness deficits, the implications of these for people with dementia and their caregivers, and the possibilities for targeted and effective interventions.

**Keywords:** anosognosia; insight; denial; self-awareness; metacognition

### Introduction

Awareness constitutes a fundamental aspect of human subjective experience, but becomes particularly salient when it is disrupted in some way, as in various neurological and neurodegenerative conditions. Here we focus on Alzheimer's disease (AD), the most frequently diagnosed form of dementia, together with associated conditions; since the issues for different dementia sub-types overlap considerably both theoretically and practically, it is appropriate to take a broad perspective. Disturbances of awareness have a significant impact on the way in which individuals experience dementia emotionally and respond to it behaviorally, affecting their readiness to engage in assessment or treatment, and their ability to maintain independent functioning. Disturbances of awareness also have implications for relationships with family members, friends, and paid caregivers, and for care provision.

For the purpose of this article, we adopt a working definition of awareness as 'a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly' (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Although the construct of awareness

has been extensively studied in dementia, few clear findings have emerged and a definitive understanding remains elusive (Aalten, van Valen, Clare, Kenny, & Verhey, 2005; Marková, 2005). The significant discrepancies among the findings of existing studies are highlighted by varied and often confusing use of terminology. Terms such as anosognosia, lack of insight, denial, and metacognition are used in interchangeable ways, sometimes without regard to their technical meanings (Marková, Clare, Wang, Romero, & Kenny, 2005). Given the various assumptions inherent in these terms, we suggest that in the context of dementia research, the term 'awareness' can be used as a general, theoretically neutral descriptor, and this term will be used throughout this article.

The aim of this article is to present a clear and accessible framework for understanding and assessing awareness in people with dementia that can guide future empirical research and help to shape clinical practice. First, we examine awareness as a theoretical construct highlighting some of the factors that are likely to influence its manifestation and stability. A distinction is then made between the theoretical construct and the clinical phenomenon of awareness, as it is the latter that becomes the focus of empirical studies. After discussing some of the factors that shape the

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experience and expression of awareness, we present a framework for delineating awareness phenomena in dementia, comprising four levels of increasing complexity. We show how this framework allows for specific phenomena of awareness to be defined and elicited. Finally, the application of this framework in the study of awareness phenomena in dementia and the resulting clinical implications are discussed.

### Awareness as a theoretical construct

Awareness is sometimes viewed as synonymous with consciousness (Zeman, 2001). Consciousness can be equated with waking state or arousal (Zeman, 1997), and has been described as a general capacity for particular kinds of inner experience (Tulving, 1993), contrasting with the state of non-consciousness in which there is no processing of information from the environment and the individual is non-responsive to internal and external stimuli (Morin, 2006). Some influential models of consciousness take a broader perspective, outlining a number of different levels and incorporating concepts of self (Neisser, 1997) and self-awareness (Humphrey, 1986). In some languages, no distinction is made between constructs of consciousness and awareness. However, researchers have distinguished between these two constructs, arguing, for example, that it is possible to be conscious without being aware (Samsonovich & Ascoli, 2005). According to this distinction, if consciousness is a general capacity for various kinds of inner experience, awareness arises when this capacity is employed in specific ways in relation to specific objects, with a fundamental prerequisite for awareness being the direction of attentional resources towards the object of awareness (Tulving, 1993). Awareness may embrace factors external to the individual, such as aspects of the environment or the behavior of others, or may be purely directed inwardly, at aspects of the self.

The cognitive processes that produce or maintain awareness may influence behavior at levels ranging from simple motor responses through to the organization of complex, goal-directed action (Stuss, Picton, & Alexander, 2001). Lower level processes function in a narrow context and include direct appraisal or description, for example of pain or noise. Higher level processes include judgments, attributions, comparisons, and reflection, for example, judgments about one's memory functioning. The scope of these higher level processes may be immediate or extended, covering past and/or future time periods; for example, the individual may compare current memory functioning with past experience in this area. Research in social cognition indicates that these cognitive processes are subject to a range of influences which may constitute barriers to accurate self-knowledge. A variety of self-serving biases may operate to protect self-esteem and psychological well-being (Gergen, 1984; Greenwald, 1980), affecting the accuracy of self-relevant appraisals

(Morin, 2006). While such processes appear to be universal, their operation may be especially evident when the individual is undergoing changes and challenges as a result of developing cognitive impairments. Motivational factors can limit the scope for accurate self-appraisal through unconscious repression and conscious suppression of unwanted memories or material (Wilson & Dunn, 2004). When an individual demonstrates limited awareness in a given domain, this may reflect pre-conscious denial, conscious avoidance, or 'covering up' where individuals provide what they perceive as an acceptable response. Situations which challenge the individual's sense of continuity are likely to provoke responses aimed at restoring the status quo; for instance, people may seek to minimize or deny their difficulties. Social influences may shape behavior and modulate the momentary accessibility of internally stored information such as that held in autobiographical memory, thus influencing the degree of awareness that is apparent to the observer. Awareness will be influenced by beliefs, norms, and expectations, which interact with motivational factors, whether internal or external, and the social context can facilitate or hinder the development or expression of awareness (Glaser & Strauss, 1965).

It follows that, in some circumstances, individuals make self-appraisals which do not correspond closely with what is perceived by others, raising the issue of the accuracy of the individual's representation. This is particularly relevant when considering clinical populations, where neurological damage can place constraints on an individual's potential for awareness (Lewis, 2003). Limitations on the reconstructive processes of autobiographical memory can affect the expression of awareness (Conway, 2005). In some situations, difficulty in laying down new episodic memories may prevent updating of the self-knowledge store, so that individuals express self-knowledge that is consistent with their earlier self but does not reflect more recent alterations or adaptations, of which they appear to be unaware (Klein, Cosmides, & Costabile, 2003; Klein, German, Cosmides, & Gabriel, 2004).

### Awareness as a clinical phenomenon

The multi-faceted and complex nature of awareness calls for a broad conceptual framework, encompassing a diverse range of possible influences when seeking to understand awareness-related phenomena in clinical situations. For empirical research, the theoretical *concept* of awareness must be translated into specific clinical *phenomena*, elicited at a particular time and a particular way (Marková, 2005). The many empirical studies exploring aspects of awareness in dementia and other conditions are characterized by marked variability and inconsistency of results. It is likely that, aside from variability in the populations studied, this reflects differences across studies in the phenomena elicited, which may be due to factors such as variations in the

concept of awareness adopted, the object of awareness selected, and the type of measure used.

The concept of awareness held by the clinician or researcher shapes the focus of inquiry and thus influences what is observed or elicited. This is apparent, for instance, when comparing research on awareness conducted from a cognitive neuroscience (Salmon et al., 2006; Shibata, Narumoto, Kitabayashi, Ushijima, & Fukui, 2008) or psychoanalytic (Weinstein, Friedland, & Wagner, 1994) perspective. In addition, the majority of research on awareness in dementia has focused on identifying correlates and predictors of impaired awareness, and has thus tended to present a picture of extensive deficits (Aalten et al., 2005), while phenomenological research has documented the degree to which awareness may be retained (Clare et al., 2008; Phinney, 2002). Studies of awareness in people with dementia have considered a wide range of 'objects' of awareness; that is, capacities or aspects of experience which are the focus of awareness. Memory loss is the most frequently selected object of awareness, and in general the chosen object shapes the phenomenon of awareness in crucial ways (Marková, 2005). When objects are more complex constructs, such as 'dementia' or 'self', the resulting awareness phenomena are likely to be influenced to a greater extent by social and cultural variables. A related consideration is the temporal scope of awareness, that is, the time period in relation to which awareness is sought or elicited, whether the immediate present, the current situation, or past or possible future experience (Clare et al., 2008). The measure used to capture awareness will contribute to the specific phenomenon elicited, partly because of the variety of scales, measures, and interviews used, and also because of the variable way in which different interviewing styles contribute to the direct and interactive shaping of the phenomenon. In research on awareness in dementia, awareness of functioning or performance is typically assessed through calculation of discrepancies between self- and informant-ratings on parallel questionnaires and between self-ratings and objective task performance, while more general awareness of the condition and its implications is typically assessed through clinician ratings and interview-based approaches (Clare, Marková, Verhey, & Kenny, 2005).

The expression or content of awareness will also be influenced by the characteristics of the sample or population being studied. People with dementia are a heterogeneous group, not only in terms of dementia type. Differences may be expected according to severity of dementia, and for a given individual, awareness may either increase or decrease over time (McDaniel, Edland, Heyman, & the CERAD clinical investigators, 1995; Weinstein et al., 1994). There may be cultural differences in normative expectations about self-expression which will influence the responses individuals give in situations where their awareness is evaluated (Prigatano, 1999). It is therefore important for research on awareness to present a clear theoretical

perspective and a precise definition of the phenomenon under study, to identify as precisely as possible the specific objects of awareness under investigation, to clearly justify the reasons for selecting particular methods, and to acknowledge the possible influence of sample-specific characteristics.

#### **A 'levels of awareness' framework for delineating awareness phenomena in dementia**

Here, we propose a conceptual scheme for delineating awareness phenomena in dementia, summarized in Table 1, which seeks to specify a range of awareness phenomena differentiated in terms of their level of complexity. In outlining this scheme, we draw upon the structure provided by models of consciousness. Most neuropsychological models of human consciousness differentiate levels or types of consciousness in terms of their complexity (e.g., Natsoulas, 1997; Neisser, 1997; Newen & Vogeley, 2003; Schooler, 2002; Tulving, 1985; Zelazo, 2004), and a common theme is a distinction between core and extended versions of the construct. Core (or 'basic' or 'primary') consciousness is the process of perceptually registering, internally representing, and behaviorally responding to current aspects of the external environment or one's internal state, is temporally and spatially confined to the immediate present (Stuss et al., 2001; Tulving, 1985), and does not require language. These minimal levels of consciousness allow the individual to interact effectively with the environment (Morin, 2006). Extended (or 'reflective' or 'symbolic') consciousness is described as involving the construction, at various levels, of mental representations of the self and the world, taking into account information from the past and the anticipated future as well as the present, and at times including thoughts and feelings about the nature of one's conscious experience (Levine, 2004; Perner, 2000; Tulving, 1985). Language is considered necessary for extended consciousness, together with the ability to reactivate personal memory (Damasio, 1999; Levine, 2004).

This distinction between core and extended levels is mirrored in the framework we propose for conceptualizing awareness, which considers awareness as operating at four levels of increasing complexity: sensory registration, performance monitoring, evaluative judgment, and meta-representation. The first of these requires only simple internal representations based on core consciousness, while the remaining three involve more complex capacities for mental representation, drawing on extended consciousness. Although for purposes of clarity, we present these levels separately, it is important to note that there may be interactions between them, that some awareness phenomena may span two or more levels, and that presentations of awareness deficits may result from problems at more than one level (M. Davies, A.A. Davies, & Coltheart, 2005). The expression of awareness at any given level

Table 1. Levels of awareness.

Level of awareness	Operations involved	Usually assessed by	Influences on the expression of awareness
Sensory registration	Registration of basic sensory and perceptual information	Observation of behavioral and/or verbal responses	Rate of occurrence of stimuli/events; sensitivity and accuracy of observation
Performance monitoring	Monitoring ongoing task performance as it occurs, and identifying errors	Comparing self-ratings of task performance with objective test scores	Cognitive function; individual psychological factors; task characteristics; and familiarity with or opportunities to engage in task
Evaluative judgment	Judgments about symptoms, changes or impairments, or specific aspects of one's abilities, performance, functioning, or situation	Comparing self-ratings with informant ratings on a parallel measure	Cognitive function; individual psychological factors; informant perceptions; informant factors; contextual factors; and characteristics of the measure used
Meta-representation	Reflection on one's situation and changes experienced, self-reflection, considering the perspective of others	In-depth interview with participant and possibly also an informant	Individual psychological factors; cognitive function; context; relationship with interviewer; and interviewer's interpretation

may be explicit, as demonstrated in a verbal response, or implicit, as demonstrated by behavioral adaptation or underlying attentional bias in the absence of explicit awareness. For a given individual, degree of awareness within any level may vary depending on the selected object of awareness.

### ***Sensory registration***

Sensory registration is based on simple internal representations, reflecting the capacity for attentional resources to be directed at an object, leading to appraisal and/or behavioral response. This capacity underpins all manifestations of awareness at higher levels. When impairments in awareness arise at this level, they are extensive and pervasive in nature (Stuss et al., 2001). However, it is likely that people with severe dementia who do not communicate verbally will continue to show some awareness at this sensory and perceptual level, which can be observed in their responses to environmental and social stimuli. Several studies have demonstrated preserved reactions to sensory stimuli in people with very severe dementia (e.g., Magai, Cohen, Gomberg, Malatesta, & Culver, 1996), and people with moderate to severe dementia who can still communicate verbally show preserved capacity for sensory registration of, and responses to, both internal states such as discomfort or pain, and environmental stimuli such as noise or change of temperature (Clare et al., 2008). While sensory registration is less likely to be influenced by intra-individual factors such as beliefs, the social and environmental contexts will affect the scope for sensory registration and expression of behavioral responses.

### ***Performance monitoring***

This level includes monitoring ongoing task performance as it occurs, comparing expected and actual outcomes, identifying any errors and evaluating success. For example, when engaged in an everyday task such as meal preparation, it is important to notice whether each successive step has been completed, and correct any errors or omissions immediately, as missing out a crucial step is likely to mean that the task cannot be completed successfully. Difficulties in such performance monitoring could arise for various reasons (Agnew & Morris, 1998), and may be associated with impairments in other aspects of executive functioning such as mental flexibility, although an association is not always found (Morris & Hannesdottir, 2004). At the performance monitoring level, objects of awareness are relatively circumscribed, and are readily measurable; task performance can be assessed and compared with self-ratings of performance (e.g., Giovannetti, Libon, & Hart, 2002). However, self-ratings of performance can be influenced by a range of factors, including beliefs and expectations, knowledge about the task, availability of feedback, and emotional

responses to perceived success or failure (West, Dennehy-Basile, & Norris, 1996). Performance monitoring could also be compromised in situations where opportunities to undertake the given task or activity are reduced.

### ***Evaluative judgment***

This level reflects the individual's general awareness of symptoms, changes or impairments of functioning in specific domains, or of aspects of his/her abilities, performance, or situation. It would include, for example, evaluation of memory functioning or general ability to drive safely. At this level, awareness phenomena are more complex since they comprise judgments of a more varied and composite nature. For example, some evaluative judgments will draw upon the ability to simultaneously consider at least two relevant mental representations and the relationship between them, as in comparisons of past and current memory capacities. Other types of evaluative judgments may involve making sense of new internal experiences and rating their impact or qualities. Such judgments are elicited in relation to mood changes, for example, in depression or irritability, or behavioral changes such as apathy or disinhibition. The composite nature of these types of judgments, however, means that the resultant awareness phenomenon is likely to be influenced to a greater extent by individual, social, cultural, and contextual factors. For example, judgments made about changes in subjective mental states and behaviors will depend not only on the way in which changes are registered, but also on a host of other factors including personality attributes (e.g., levels of confidence, ability to articulate, or tendency to introspect), past experiences, social/cultural niche (e.g., degree to which subjective 'impairments' or 'weaknesses' may be understood or accepted in the individual's environment), and so on. Likewise, judgments made about changes in ability to do particular tasks will also be influenced by these types of factors. An individual who has always placed a high value on his or her effectiveness in carrying out practical tasks might assess and rate changes in abilities in this domain in a different way from someone for whom such things are less important. In the case of awareness of memory impairment, evaluative judgments may reflect the ability to extrapolate from a number of task-specific instances, compare past and current functionings, and identify the presence of difficulties or changes. In addition, these judgments will be influenced by other factors. For example, judgments about such memory changes made in the context of feeling distressed or angry may be different from those made when feeling well. Thus, evaluative judgments are likely to be influenced strongly by beliefs and attributions that reflect general expectations, social stereotypes, and emotional responses. Difficulties with evaluative judgments at this level become evident when

the beliefs or concepts expressed are clearly discrepant with the objectively observed situation. If there is no awareness of impairment, then clearly evaluative judgments concerning the effects of the impairment are not possible.

The capacity for evaluative judgment is most often assessed through comparison of self- and informant-ratings in specific areas of interest, such as memory functioning. Establishment of the accuracy of such judgments is clearly not straightforward, as attributes of an individual's experience may be hard to define or grasp. Accuracy is often determined by comparing the individual's own account with an appraisal made by an informant, but the informant's appraisal may itself be subject to influence or bias; for example, a carer who feels extremely stressed or depressed might provide an unduly negative appraisal of the way in which the person with dementia is functioning in a given domain. Evaluative judgment can be seen as dissociable from performance monitoring, since individuals with dementia can identify task-specific errors and nevertheless maintain that they have no memory difficulty beyond normal aging, or *vice versa*. However, these two levels may interact. In relation to hemiplegia, it has been argued that unawareness of impairment is related to the interaction between two main factors: a problem with detecting incongruence between expected and actual experience, giving rise to what are perceived as unusual experiences, and an abnormality in belief evaluation, affecting the ability to make sense of the experience (Davies et al., 2005).

### **Meta-representation**

The meta-representational level is the most complex aspect of awareness, incorporating self-reflection and ability to consider the perspective of others. Examples include awareness of being considered to have a given illness or diagnosis, and of the implications of this for the self and/or for others, as well as awareness of the impact on self and/or others of particular symptoms or changes in everyday life, both in the present and in the future. At the meta-representational level, the objects of awareness are broad constructs, for example, illness, personality, or aspects of self. Such objects are not clearly delineated, and they depend not only on experiential changes but also on social, cultural, educational, and individual influences. The clinical phenomena determined by these broad objects demand judgments on the part of the individual that reach out to diverse aspects of the individual's knowledge and experience, and will be shaped by the individual's emotions and attitudes, and by cultural perspectives, as well as by the extent to which the individual's context supports the process of reflection. The clinical phenomena thus have to incorporate a range of heterogeneous judgments, diverse in content, type, and complexity.

The levels of awareness framework presented here is intended to provide a structure for understanding awareness at different levels, moving from sensory and perceptual registration through higher order judgments to meta-representation or knowledge-based accounts. It provides a basis for specifying the relative contributions of neurological, cognitive, psychological, social, and environmental factors to the experience and expression of awareness at each level. Available models specifying the cognitive processes and structures underpinning specific aspects of awareness can be aligned with this framework. One such model is the Cognitive Awareness Model (Agnew & Morris, 1998; Hannesdottir & Morris, 2007; Morris & Hannesdottir, 2004) of reduced awareness of memory loss in AD, which focuses particularly on the cognitive processes implicated in impairments of awareness at the levels of performance monitoring and evaluative judgment. The levels of awareness framework also point to the importance of considering the motivational processes and social influences that shape individual reflection and appraisal (Marková, 2005). Lack of awareness should not be regarded simply as a symptom of dementia; instead, a comprehensive understanding of awareness requires a biopsychosocial perspective on its constituent phenomena, and of the influences which affect each of them (Clare, 2004; Clare et al., 2011).

### **Future directions for research on awareness in dementia**

The framework outlined in this article distinguishes different levels of awareness, each of which involves different kinds of cognitive processes and is influenced to varying degrees and in various ways by individual and contextual factors. It follows that the clinical phenomena elicited at each of these different levels are not directly comparable, and it may not be legitimate to generalize from results obtained with regard to a particular level and object of awareness to other levels and objects of awareness. Precise specification of the awareness phenomenon under consideration, using the framework outlined here, will help to improve the coherence and clarity of the research evidence and hence enhance our understanding of the nature of awareness difficulties and the way in which awareness may change over the course of dementia. Modeling the factors and mechanisms associated with awareness in dementia can provide insights into how these operate and how awareness becomes disrupted, as well as giving rise to predictions which can be tested by further experimental study. A key aim of research in this area should be to explore the influence of cognitive, psychosocial, and environmental factors on awareness, and to attempt to distinguish those aspects that are the direct result of disease-related pathology from those that reflect emotional or behavioral responses to the impact of the condition.

The ability to make this distinction will have important implications for decisions about treatment and care.

### **Clinical implications and applications**

There have been few attempts to conduct interventions directly aiming to increase awareness in people with dementia, and few attempts to educate caregivers about the nature of retained and impaired awareness. However, understanding awareness may be important for caregivers, and while it would seem inappropriate to force people with dementia to confront and reflect on the implications of their condition, there may be ways in which supporting awareness could be helpful. The conceptual scheme outlined in Table 1, by clarifying different levels of awareness, can assist in identifying implications for care and treatment at each of these levels.

### ***Sensory registration***

There are particular implications for the care of people in the severe stages of dementia, namely sensitivity to signs of preserved awareness, and provision of appropriate environmental stimulation to support its expression. Care staff could be trained to observe and understand behavioral indications of awareness (Clare, Woods, Whitaker, Wilson, & Downs, 2010), and to find ways of increasing the experience and expression of awareness through, for example, sensory stimulation, postural change, or environmental adaptation.

### ***Performance monitoring***

The ability to estimate one's own performance accurately is important for managing everyday situations safely and effectively, and for remaining independent (West et al., 1996). It is also important for psychological well-being, since overestimation of ability carries risk of failure, while underestimation could lead to avoidance of activities and further loss of skills and confidence. Interventions could aim to improve accuracy of performance monitoring in real-life situations in order to support effective coping.

### ***Evaluative judgment***

The central issue is likely to be that of managing the discrepancies between the views held by the person with dementia and those of significant others. If the person with dementia attributes forgetfulness to normal aging, this may represent a way of coping with the situation, and it would not necessarily be desirable or appropriate to confront and contradict such beliefs. However, inaccurate judgments are likely to cause concern to caregivers and to create many practical difficulties. Interventions might focus on negotiating areas of common ground (e.g., Whitlatch,

Judge, Zarit, & Femia, 2006). Equally, since evaluative judgments may change over time, it may be valuable to provide support that could potentially facilitate developments in coping style. Early-stage support groups might have a role to play in this process (Logsdon et al., 2010). In the moderate to severe stages of dementia, where difficulties in evaluative judgment suggest that the person is struggling to make sense of what seems like a puzzling current situation, the provision of enhanced contextual cues and environmental support may be helpful.

### ***Meta-representation***

Providing a context in which complex issues can be reflected upon and discussed (Glaser & Strauss, 1965) is central to preserving or enhancing awareness at this level. While it would be inappropriate to force a person with dementia to reflect on the experience of having the condition and its implications, it may be important for some individuals to have this opportunity, for example through support or psychotherapy groups (Watkins, Cheston, Jones, & Gilliard, 2006).

### **Conclusions**

A range of conceptual and methodological issues, as well as inconsistent application of terminology, have contributed to a lack of clear research evidence regarding awareness in dementia. In an attempt to increase conceptual and methodological clarity, we have argued that it is advisable to specify the level of awareness under study as well as the object in relation to which awareness is assessed. We have defined four levels of awareness, each involving different processes: sensory registration, performance monitoring, evaluative judgment, and meta-representation. Awareness at each level is not only simply determined by cognitive capacity, but also subject to a range of psychosocial and environmental influences; the relative impact of these influences increases along with the degree of complexity involved. Modeling the factors and processes involved in determining awareness phenomena leads to predictions that can be tested empirically. Key theoretical challenges for future research will be to identify the distinct influences and contributions of neurocognitive and socio-environmental factors, and to clarify which awareness phenomena are amenable to appropriate and sensitive intervention. Key challenges for clinical practice will be to identify where it is appropriate to attempt to increase awareness and where it is preferable to find ways of managing unawareness, and to help family members and paid carers understand the nature and extent of the person's awareness and tailor their interactions accordingly. While we have focused on awareness in people with dementia, some of the principles outlined here will also be applicable to awareness phenomena in other conditions. Understanding and working effectively

with awareness phenomena has the potential to reduce disability and enhance well-being, and further knowledge in this area should therefore be vigorously pursued. The approach presented here provides a framework for future research that will help to insure the applicability and utility of findings for the benefit of all those affected by difficulties with awareness.

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