Advance care planning for people with dementia: benefits and challenges

Debbie Dempsey

The profile of advance care planning (ACP) has been raised in recent years, with various publications emphasising the importance of identifying people’s preferences, wishes, and expectations for their future care (British Medical Association, 2007; Department of Health (DH), 2008; Royal College of Physicians (RCP), 2009). It has been suggested that ACP can enhance end-of-life care by allowing patients to discuss and record their future health and care wishes (Thomas and Lobo, 2011). Several authors have highlighted the sense of control it gives the individual in preparing for the future and not feeling a burden to others (Smith, 2000; Detering et al, 2010).

The importance of this process taking place prior to loss of mental capacity is increasingly being acknowledged. Robinson et al (2011) wholeheartedly support its use in dementia care, where they believe loss of capacity is inevitable. This opportunity to empower decision making and promote person-centred care underpins the whole philosophy of palliative and end-of-life care and links with the World Health Organization’s (WHO, 2013) definition of palliative care, which focuses on facilitating a team approach in which patients’ and families’ needs are assessed effectively.

The reality of ACP for people with dementia is unfortunately less grounded in clinical practice. In their review of the topic, Dening et al (2011) stated that few people with dementia make advance plans. Given the rising numbers of people affected by dementia, including 64% of those residing in care homes (Alzheimer’s Society, 2012), there is a need to examine this lack of provision. This paper aims to review and evaluate the literature surrounding ACP and dementia and provide clarity on the perceived challenges and barriers to ACP implementation with this client group. It also critically appraises the documented benefits of the process, while considering the place of dementia generally in the palliative care forum. Links to recognised ethical and legal dilemmas are made in an attempt to examine how future practice can be influenced and shaped to ensure ACP in dementia is viewed as a necessary, achievable process.

Dementia and its place in palliative care

Palliative care in its truest sense affirms life and views dying as a normal process (WHO, 2013). The National Institute for Health and Care Excellence (NICE, 2004) described the integration into palliative care of psychological and spiritual dimensions and the need to embrace the principles of good palliative care early in the disease journey, regardless of whether an individual has cancer or other life-limiting illness. Dementia is now increasingly being included in the realm of life-limiting conditions perceived to require palliation; however, this realisation has been a long time coming. Stokes (2011) emphasised the breadth of work yet to be done in order to widen accessibility for this client group, as did Hughes et al (2007), who highlighted the moral need for end-of-life care in dementia to be improved. Earlier work by Ahronheim et al (1996) appraised the differences between end-of-life care in cancer and dementia, and found that people...

Abstract

Advance care planning (ACP) is a process being championed within health and social care, particularly since the publication of the UK Department of Health’s 2008 End of Life Care Strategy. However, its implementation in dementia care is yet to be fully realised and can pose significant ethical and legal dilemmas for the generic and specialist workforce, the patient themselves, and their family or loved ones. Challenges may be attributable to inadequate communication, capacity issues, missed opportunities, and the perception that dementia is not a life-limiting illness. The aim of this paper is to highlight the benefits of ACP for individuals with dementia while appraising the recognised barriers to assist in developing some realistic recommendations for future practice.

Key words: Dementia • Capacity • Best interests • Preferences • Planning • Autonomy • Respect

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with dementia were subjected to more prolonged, invasive, and inappropriate interventions. More recent work by Thune-Boyle et al (2010) corroborated this theory; however, there needs to be greater clarity on the triggers for this pathway and the identified areas for development.

The UK Government has been influential in raising the profile of mental health services and palliative care. For example, the Care Services Improvement Partnership (2005) demanded equal access to palliative and end-of-life services for people with dementia. The DH's (2009) National Dementia Strategy has also been key in bridging the chasm between dementia and palliative care as it clearly indicates that dementia needs to be considered a disease from which people die. The strategy presents the stark reality of a population of 1.4 million people in the UK with dementia in the next 30 years and the staggering cost to the national economy. It advocates timely planning and provision of information and a general shift toward embracing rather than avoiding ACP (Box 1); however, it must be acknowledged that the strategy may not be rolled out at a local level, with over 30% of health trusts lacking robust plans for implementation of the recommendations (Ramesh, 2010).

Why advance care planning?
ACP is defined as:

‘A voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline.’ NHS End of Life Care (2008)

It is accepted that ACP may include family and friends and that, with consent, the discussion is documented, communicated to all relevant personnel involved in the person's care, and reviewed. Horne et al (2009) broadly categorised the goals of ACP as ensuring that care respects patients’ preferences, facilitating shared decision-making and enhancing quality of life by ensuring appropriate treatment. Recognised for its wealth of benefits to patients, families, and health and social care staff, it appears to be more easily accepted within the cancer arena (Hertogh, 2006). However, its use in dementia care is crucial to ensuring patients with dementia receive the same opportunities for end-of-life planning as those with other life-limiting illnesses. This is endorsed by the NICE and Social Care Institute for Excellence (2011) guidance, which recommends that commissioners ensure early diagnostic and assessment services to promote the provision of information at a time when the person with dementia still has capacity. According to Xie et al (2008), the life expectancy for a person with dementia is 4.5 years, hence waiting until the terminal phase may mean that care is uncoordinated, inappropriate, and undesirable.

Further incentive for ACP relates to preferred place of death, with figures highlighting that despite around two thirds of people wishing to die at home, less than a third actually do (Higginson and Sen-Gupta, 2004). This issue was explored by Holman et al (2011), who discussed the difficulties that care home staff face when residents with dementia are admitted to hospital in the last few days of life owing to a lack of formal documentation, particularly relating to resuscitation status. This issue has undoubtedly contributed to the development of core competencies for those working with adults at the end of life (DH et al, 2009), with ACP felt to be a priority alongside communication skills, assessment and care planning, and symptom management. The relevance to people with dementia is clear if we as a society are to embrace their needs, particularly when they reach a point where comfort measures may be preferable to invasive intervention.

Professionals’ views and confidence
Hertogh (2006) felt that the lack of ACP with dementia patients is partly due to physicians’ lack of experience. He acknowledged the need for specific training and highlighted the difficulties in categorising dementia severity, as cognitive and functional disability may not necessarily correlate with life expectancy.

Robinson et al (2013) attempted to gauge the views of professionals working with dementia on how ACP is implemented. They identified that ACP is not something routinely considered part of dementia services. When carried out, it tends to come very late in the disease trajectory, resulting in anxiety for proxy decision makers. These findings concur with earlier work by Happ et al (2002), who studied the use of ACP in a Jewish nursing home. They found that ACP was primarily addressed on admission in the form of discussions regarding cardiopulmonary resuscitation.
concluded that there was a tendency to limit ACP to few choices for care home residents, and that the wider range of personal preferences and expectations was not explored. There appears to be a consensus on the gap in ACP provision for dementia patients, and this is corroborated by similar data indicating that hospice services are often underutilised by this client group, with input often delayed until the week before death (Matthews and Dening, 2002).

Sachs et al (2004) attempted to provide further reasons for professional avoidance of ACP for people with dementia, and believed that often practitioners struggle to view dementia as a life-limiting disease. They emphasised that physicians are often tentative in referring patients with dementia to hospices and felt that this is due to the lack of reliable prognostic indicators and variable survival rates. This is of concern and may provide a clearer picture of why ACP is not carried out routinely on diagnosis. In the UK, this issue has been considered by the implementation of the Gold Standards Framework (GSF) (National Gold Standards Framework Centre, 2008), which provides clinical indicators that suggest someone with dementia may be entering the end stage of their disease. These guides are valuable for staff who may lack the confidence to diagnose dying in non-malignant diseases, although they only form part of the holistic assessment process.

The anxiety that health and social care professionals can often feel in initiating ACP conversations was explored by Thomas and Lobo (2011), who categorised the barriers succinctly as lack of knowledge, discomfort, lack of time, and language and communication difficulties. These barriers were confirmed by the Commission for Social Care Inspection (2008), who highlighted inadequacies in communication in care homes, citing task-orientated approaches to dementia with a clear lack of empathy and warmth. Stevens and Whyte (2011) suggested that staff might also not know who is the best person to have these discussions. Their study emphasised the importance of knowing the patient well, but highlighted the conflict between senior nurses and health-care assistants, with the former believing discussions were solely their responsibility. Stevens and Whyte (2011) proposed the inclusion of health-care assistants in education, given that they are privy to sensitive information when providing intimate care.

**Views of family/loved ones**

Hertogh (2006) emphasised the relevance of ACP for the families or significant others of individuals with dementia. He reminded us that families not only have to deal with the perceived loss of their loved one before their physical death, but also relinquish their caregiver role to others on admission to a care home. This stress is often compounded by the agonising moral and ethical dilemmas they face when deciding the best course of action for their relative or friend. Caplan et al (2006) acknowledged this point, lamenting that hospital admission for dementia patients is an unsurprising result of this poor communication system and the apprehension of families in wanting to seek the best treatment in an uncertain situation. Henderson (2006) found that similar issues dominated, and highlighted that there were limited discussions with family members around end-of-life preferences and choices. This work echoed the research carried out by Murray et al (2005), who felt that ACP is often considered only at the terminal phase of the illness, yet needs to be embedded in practice from diagnosis. A report by the Healthcare Commission (2008) stated that families will often identify their loved one is deteriorating, but complaints arise owing to their perceived lack of information, options, and support in the decision-making process.

The Mental Capacity Act 2005 (Department for Constitutional Affairs, 2007) makes provision for appointing a Lasting Power of Attorney (LPA), a concept intended to pre-empt the difficulties faced by patients lacking capacity. Livingston et al (2010) appraised the idea of LPAs, yet discussed how carers may unfortunately face conflict with what their loved ones had previously expressed and with changing circumstances. This demonstrates the potential stress faced by the carer in an already difficult situation. Papworth (2012) agreed that although this provision is intended to be theoretically uncomplicated, some financial institutions are particularly bad at dealing with people trying to exercise their rights as LPAs. The need for a more collaborative approach to ACP and dementia is recognised, as formal directives require an appreciation that families remain vulnerable when asked about best-interest decisions.

In trying to engender a collaborative approach to dementia and end-of-life care, Alzheimer Scotland (2009) developed their ‘Beyond Barriers’ project, which developed action learning sets for care home staff and joint training for
Box 2. Recommendations for ACP in dementia*

- Skilled interviewer
- The right time, e.g. supportive post-diagnostic counselling processes
- The right place—quiet, unthreatening place with no distractions
- Involvement of family
- Take time
- Scenarios—clinical vignettes, picture cards, videos
- Life story

*Conroy (2009)

relatives and staff. The merits of action learning were discussed by Brockbank and McGill (2007) and relate to the problem-solving techniques that can be initiated by discussing real issues with relevant colleagues. Similar education programmes have been devised both nationally and across Europe, with Caplan et al (2006) advocating the use of their specific model, which involved training GPs. A qualitative element of their research highlighted a reduction in hospital transfers from care homes, while a qualitative component demonstrated a shift in culture relating to ACP. Hertogh (2006) considered the benefits of this study but felt strongly that ACP alone will not ensure quality end-of-life care in dementia. He alluded to the theory that poor medical support and symptom management and tardy diagnosis all challenge attempts to palliate effectively in dementia. His criticism of Caplan et al (2006) focused on the omission of any provision and structure of palliative care intervention, once the decision to forego hospitalisation is made. Hertogh (2006) believed the ‘Dutch’ model was more proactive, as in the Netherlands nursing homes are staffed by trained physicians who have the necessary experience to manage long-term conditions, including advanced dementia. Hee et al (2003) also recognised the benefits of this approach in terms of the doctor developing a sound understanding of their patients' needs and the ability to connect with families, promoting timelier end-of-life discussions.

Giving the dementia patient choices

Conroy (2009) challenged the perception that the process of ACP is traumatic and pointless for those with dementia. He believed that such discussions can take place even though the individual might have relatively advanced disease. This notion was endorsed by Fazei et al (2000), who provided evidence that, following diagnosis, patients want the opportunity to discuss their preferences and may make similar decisions to those without dementia. Shega et al (2003) concurred and believed that many people will readily enter into these types of discussions and may feel relieved the issue has been raised. They provided further data to support this approach in the community and highlighted the benefits in relation to proactive symptom control and respect for patients' wishes.

Effective communication is understandably imperative to the ACP process and Conroy et al (2009) provided tips for discussions with dementia patients that consider the optimum environment, involvement of family, and the use of clinical vignettes to illustrate clinical scenarios (Box 2).

Provision of information in the right format is often overlooked according to Thomas and Lobo (2011), who appraised the merits of basic principles such as choosing the most conducive time of day and not rushing the process. This can be challenging for staff, who may feel resources are stretched; however, the authors believed that investment in ACP will ensure seamless provision of care when the person with dementia deteriorates. Their work emphasised the onus practitioners place on written and verbal information, when simpler visual techniques may be more fruitful. Houts et al (2006) acknowledged the use of imagery in improving provision of complex health information.

This issue was explored further by Volandes et al (2009), who evaluated the use of a video decision support tool with dementia patients. They advocated the visualisation of a hypothetical health state in improving decision making. Their research involved two groups, one of which received a verbal narrative describing advanced dementia and the other of which also viewed a video depicting the key characteristics of advanced dementia. Participants were interviewed immediately following the intervention and 6 weeks later and were asked about their preferences for future care in that situation. Among the group who received only the verbal narrative 64% chose comfort care whereas 86% of the video group opted for the same. Volandes et al (2009) evaluated the stability of preferences at the end of life by examining them 6 weeks later, and found that the proportion of participants changing their preferences was lower in the video group. This work is paramount in providing the rationale for the use of video information to aid understanding; however, it must be considered that videos can be biased in favouring a specific ideology. The film in Volandes et al's (2009) work used a white woman with dementia, and participants were primarily white or African American. The findings may have differed with other minority groups, as previous studies have suggested that non-white people are...
inclined to pursue more active, aggressive end-of-life care (Crawley et al, 2000; Hopp and Duffy, 2000). This work could potentially be developed further to include participants diagnosed with early dementia, as opposed to creating hypothetical situations. However, this may pose a conflict between balancing the benefits of providing patients a 'glimpse into their future' and the potential distress this may cause.

The subject of distress was discussed by Regnard (2011), who examined the multifaceted dimensions of dementia. Professionals may be inclined to promote non-maleficence by unintentionally blocking patients from expressing their preferences for fear of upsetting them. Thomas and Lobo (2011) believed this could be damaging for the person with dementia and argued that the real distress is the existential or spiritual pain associated with loss of control. They likened loss of capacity to the loss of self and advocated ACP as a means of the person maintaining their individual identity.

Advance care planning tools

Brown (2011) believed that the success of ACP tools is as much about commitment from staff, context of care, and robust models. He believed strongly that the UK needs to learn from practices in the USA, where the Patient Self-Determination Act 1991 paved the way for the ACP process, and the emergence of models such as Five Wishes (Aging with Dignity, 2012) continues to integrate legal, physical, spiritual, and emotional needs. In the UK, the Preferred Priorities for Care (PPC) document was supported by the National End of Life Care Programme (2011) as an end-of-life tool. Although initially only used for cancer patients in the community, its use has developed across various care settings to allow inclusion of patients with non-malignant diseases, including dementia. Evaluation of the earlier document was shown to result in more people receiving care in their place of choice (Wood et al, 2007). However, this research emphasised the need for education prior to using the tool. This issue was also of concern to Cohen Fineburg and O'Connor (2011), who also questioned the efficacy of the PPC as they believed it encourages patients to make choices that may be unachievable. Laycock (2011) evaluated the effectiveness of the PPC in her locality and concluded that the majority of patients only detailed place of care at the end of life, rather than identifying the broad range of preferences. She suggested this may be due to the dominance of outcome measures monitoring place of death and, although this is important, she wondered whether we are missing valuable diverse data reflecting an individual's beliefs, expectations, and wishes. Laycock (2011) discussed her local response to this issue and described the 'Think About It' tool (Table 1), which aims to prompt patient-led communication and serve as a precursor to use of a specific ACP document.

The availability of documentation for dementia patients needs to be addressed further, as there is a clear lack of published literature pertaining to the use of specific tools for dementia patients. This paper emphasises the need for early discussions that may facilitate the completion of advance statements and decisions. Although NHS Gloucestershire (2010) attempted to widen the accessibility of ACP by developing a tool that provides information for patients on the options available should capacity be lost, it is unclear how successful the implementation has been with the dementia client group.

Legal and ethical issues

In England and Wales, the Mental Capacity Act 2005 has provided the necessary statutory framework within which ACP must be used. The legislation allows individuals with capacity to nominate people who they would or would not wish to be consulted in the event of a decision, should they lose capacity. Within the scope of the act there is also provision for appointing an LPA and identifying specific treatments the person may wish to refuse. Although this framework is undoubtedly vital to the whole process of planning for the future, it also clearly demonstrates the intricacies and dilemmas faced during the process. George (2011) championed ACP in terms of respecting autonomy and improving end-of-life care; however, he reminded us that refusal of specific treatments and reducing suffering can raise profound, deep-seated issues that require a degree of social and moral responsibility. He advocated the need for critical appraisal to ensure the right outcomes are delivered.

### Table 1. Overview of examples of ACP tools currently in use

<table>
<thead>
<tr>
<th>Name of tool</th>
<th>Overview</th>
</tr>
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<tbody>
<tr>
<td>Lancashire and South</td>
<td>8 pages: advance statement, communication page, no provision for advance decision to refuse treatment</td>
</tr>
<tr>
<td>Cumbria Cancer Network's 'Preferred Priorities for Care'</td>
<td>Prompts discussion of 12 topics including organ donation, memory boxes and letters, spiritual care and religion, and family, friends, and pets</td>
</tr>
<tr>
<td>East Lancashire Hospice &amp; NHS Blackburn's 'Think About It'</td>
<td>5 sections (19 pages): statement of wishes and care preferences, advance decision making, putting affairs in order, making a will, funeral plans</td>
</tr>
<tr>
<td>NHS Gloucestershire's 'Future Planning for Your Future Care'</td>
<td>8 pages: advance statement, communication page, no provision for advance decision to refuse treatment</td>
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</tbody>
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Autonomy from an existential viewpoint suggests that the individual's desires override anything else; however, Munday et al (2009) alluded to the communitarian view, whereby a sense of self is guided through religious, family, and tribal membership. They illustrated this by describing end-of-life preferences as fluid and changeable according to the actions of the group.

Capacity issues are seen to be one of the biggest challenges to ACP in dementia (Livingston et al, 2010), with capacity defined in the Mental Capacity Act 2005 as the ability to 'understand, retain, and weigh information and then communicate one's decision'. Principles of ACP encourage planning at a point prior to losing capacity; however, George (2011) emphasised the difficulties associated with assessing capacity and competence. He described transient circumstances whereby capacity can be impeded, such as when experiencing pain and depression. Irwin et al (2008) provided further challenges by proposing that cognitive impairment in dying patients is often unrecognised, yet meets the DSM-IV criteria for dementia. Judgements made by health professionals in dementia care have the potential to obscure or cloud the patient's wishes. The duty to protect NHS budgets by deeming a treatment futile and researchers' possible desire to gain knowledge from attempting treatment also contribute to the vulnerabilities of the patient with dementia. As professionals, we may view the individual's quality of life as poor; however, Bernheim et al (2008) felt that this preconception was a potential hindrance of ACP. They argued that there are many people living with profound disabilities who consider their life worthwhile, and that kneejerk reactions may influence planning for those unable to speak up for themselves. It would seem then that the practical implications of ACP need to incorporate fluidity, realistic timescales, and regular review.

Livingston et al (2010) reminded us of the reality of ACP in advanced dementia, i.e. that decisions often have to be made on behalf of people lacking capacity. In the UK, proxy decision making by families is commonplace, with relatives having high levels of involvement in this process. Livingston et al (2010) conducted a study to identify the common difficult decisions informal carers have to make on behalf of the person with dementia. They identified that often fatigue and a lack of clear options made the decision hazy and that financial and legal issues were sometimes tackled in the context of professional and family mistrust and cynicism. ACP occurring early in the dementia journey is therefore justified in terms of human freedom and promotion of autonomy; however, it must be remembered that the process can also be fraught with ethical dilemmas and the risk of disempowering a person's evolving preferences and wishes. The need to assume and maximise capacity lies at the heart of the Mental Capacity Act 2005 and is particularly important in terms of not removing the rights of those who are vulnerable.

Future practice

The National Dementia Strategy (DH, 2009) advocated a need to educate both the health and social care workforce and the public. Campaigners such as Dying Matters (www.dyingmatters.org) are attempting to remove the stigma attached to talking about death and dying and clearly place dementia within this work. Opportunistic education should be embraced by health and social care professionals, as they are often viewed by patients and carers as a source of knowledge and wisdom (Bastable, 2003).

Education is an integral component of ACP according to Thomas and Lobo (2011), who recommended core competencies for staff that integrate good communication skills, legal and ethical awareness, and recognition of when ACP may be appropriate. This approach was corroborated by the RCP (2009), who suggested that training should be workplace-based and endorsed its inclusion in quality outcomes frameworks, which should annually review the care of patients with long-term conditions. The GSF programme will continue to remind practitioners that palliative care is about more than just cancer and can transcend all care settings to promote a seamless service. In the same way, local enhancement schemes may provide the impetus needed for GPs to engage with ACP. It may be that GPs can look at providing an enhanced service to care homes, achieving preferred place of care and using prognostic indicator tools such as the Barthel index (Mahoney and Barthel, 1965) to evidence stage of dementia.

The author's experience suggests that dementia is frequently not considered a life-limiting illness, and that this may hinder the ACP process. According to Evans et al (2010), staff fears and uncertainty in the midst of difficult circumstances can hinder the communication process; however, the National Council for Palliative Care (2009) cautioned against holding back from asking people with dementia their views as this may be a missed opportunity to provide patients with true patient-centred care. The importance of communication skills training cannot be underestimated, yet surely the possession of fundamental characteristics provides the basis on which ACP can be
built. Rogers (1995) described the components of a therapeutic relationship as 'acceptance, understanding and genuineness', and it would seem that these are key to encouraging a patient and their loved ones to disclose their real concerns and express their preferences. That aside, formal communication skills training may increase staff confidence; however, it must respect faith, culture, and life choices.

The need for more robust research into dementia has been clearly demonstrated recently by Alzheimer's Research UK (2012), who highlighted the insufficiencies in their capacity to continue to provide in-depth analysis. This has prompted the government to pledge an increase in public funding and has raised the profile of dementia in the UK and globally.

In the author's locality, a draft ACP document has been produced that includes provision for advance statements of preferences and wishes, and the more formal legally binding advance decisions. This work builds on the PPC document and it is intended that it will be piloted in the local memory clinic to evaluate its effectiveness with dementia patients and their families. This initiative aims to complement the work already being done by the ACP facilitator for care homes, which adopts an educational approach to teach nursing home staff of all grades the principles of ACP and the relevance to their clinical work. Perhaps greater education in nursing and medical curricula may be a proactive step in equipping the future health workforce with the necessary skills and awareness of dementia. This was highly recommended by Sachs et al (2004), who felt it would ripple out to greater numbers of staff.

Conclusion

The whole ethos of ACP suggests great benefits, not only for the patient but also for their families and professional caregivers. This is particularly poignant when planning ahead for people with dementia as the loss of control in decision making can contribute to the manifestation of spiritual pain and the perceived loss of self. This paper has explored some of the key challenges to carrying out ACP with dementia patients, which include communication difficulties, lack of knowledge, and the assumption that dementia is not a disease from which people die. It is clear that ACP must be high on the priority list for commissioners, as delivering it undoubtedly requires competencies and resources, which may need additional investment. Both the End of Life Care Strategy (DH, 2008) and the National Dementia Strategy (DH, 2009) have provided health and social care professionals with the necessary guidance to ensure their care is aligned to national recommendations, but most importantly they recognise the importance of integrating dementia into palliative and end-of-life care. As both publications advocate ACP as a quality marker, this process should not discriminate against age, disease group, or ethnicity and should be viewed as a process that enables patients with life-limiting disease to live well until they die. The need to explore a patient's preferences and wishes early in the disease trajectory is crucial to dementia care if we as a society are to eliminate the inequity faced by this disease group and support their loved ones through a difficult journey in the most effective way.

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... ACP must be high on the priority list for commissioners, as delivering it undoubtedly requires competencies and resources, which may need additional investment.


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