

Alzheimer Scotland

Proposals to Introduce a Statutory Duty of Candour for Health and Social Care Services

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications. Alzheimer Scotland welcomes the opportunity to contribute to the consultation on the proposals for a statutory duty of candour in health and social care services.

General Comments

Alzheimer Scotland does not believe that the use of the phrase candour within this consultation is particularly useful. We believe that 'candour' is an approach to professional practice within health and social care settings which cannot be legislated for. As such, we believe that a more helpful term would be disclosure.

Alzheimer Scotland believes that the approach of the consultation document comes from an overly health and medical perspective, noting the consultation document states that:

The proposals build on the progress made through the implementation across NHSScotland of the 'Learning from adverse events through reporting and review: A national framework for NHSScotland'.

And that:

The testing that is currently ongoing within NHSScotland on 'Being Open' guidance is also likely to be helpful in framing stakeholder engagement and the further development of proposals.

Whilst Alzheimer Scotland understands that within healthcare settings this statutory duty of candour builds upon existing practice around patient safety, we are concerned that this focus may not adequately consider current differences with social care settings and organisations. Furthermore, we note that the use of terminology within the proposals such as 'patients' and 'care episodes' would not normally be used outside of a clinical setting.

The guidance should therefore be revised insofar as it should look to approach the duty of candour, and any accompanying guidance, in a way which is suitable for use in both health and social care settings.

In addition, the consultation document does not create a sufficient distinction between the need for health and social care organisations to report to the individual as well as their

obligation to report publicly. Any legislation or accompanying statutory guidance must make these respective obligations clear.

Culture organisational ethos

Alzheimer Scotland notes within the consultation document that:

The observations made by Healthcare Improvement Scotland are consistent with observations from work that has shown that ethical and policy guidance has largely failed on its own to improve rates of disclosure.

Whilst we strongly welcome the proposals for a statutory duty of candour in health and social care settings, we believe that this demonstrates that a wider cultural shift must be adopted within the health and social care sectors. This will require a shift in approach and ethos by the institutions and organisations providing health and social care services, and this must include changes to the training and professional standards adhered to by staff. It is therefore appropriate that the Nursing and Midwifery Council (NMC) and the General Medical Council (GMC) are undertaking a review of the professional codes of ethics to create a consistent approach to 'candour'. We believe there would be merit in all health and social care professionals receiving training in the importance of 'candour' within their respective services. NHS Education for Scotland and the Scottish Social Services Council (SSSC) both have a crucial role to play in delivering the desired changes.

If a culture of openness is to be achieved, staff must trust the system and organisation to place an emphasis on learning and development to ensure an incident will not recur, instead of a focus on punitive or disciplinary matters. This must be facilitated in circumstances which may be difficult and emotive, during investigative processes. As part of this, health and social care organisations must support transparent practices which must be driven by strong leadership from management which fosters a culture of professionals accepting responsibility and accountability as part of their role.

Proposed requirements on organisations

Alzheimer Scotland broadly supports the proposed requirements on organisations once an 'adverse event' has occurred and considers them to be detailed and clear. However, we do have some comments on specific aspects of the requirements.

We note in section 5.1 that the duty will apply to:

NHS Boards, Local Authorities, all organisations providing services regulated by the Care Inspectorate, independent hospitals, independent hospices, General Practices, community pharmacies, dental practices.

Section 6.1, 'as soon as is it is reasonably practicable after becoming aware that there has been [an] adverse event resulting in harm', is vague and open to different interpretation. This should be reworded to provide greater clarity, or timescales should be set out within any accompanying statutory guidance.

Section 6.3, *'there must be an offer of reasonable support provided to the person harmed, relatives and staff who have been involved with the event'*, is too vague. As noted in the previous section, the support for staff will be a decisive factor in the success of the introduction of a statutory duty of candour and accordingly, this should be clarified.

Any accompanying guidance on this area must make clear to all health and social care organisations their obligations and the importance of fostering a culture of open and transparent disclosure. In addition it should contain:

- Information on the best way to support staff involved, with an emphasis on learning from incidents and preventing any recurrence.
- Clear information on reporting procedures, with relevant case study examples.

Furthermore, people who use services, their families and carers must have confidence and assurance that the organisations appreciate and can undertake to resolve instances of harm occurring, dealing effectively with any physical, psychological or emotional implications that arise as a result of the adverse event. We therefore believe that there must be a minimum level of support detailed within the legislation. Any accompanying guidance should offer examples of the types of support available and case studies which services may consider in different settings. This may include the use of counsellors who may be able to help support people who use services, their families and carers, and to help staff manage difficult conversations which may take place during the disclosure of the occurrence of an adverse event. In addition, Alzheimer Scotland believes that, as part of this new legislation and as part of the support following an adverse event, services must be obliged to offer independent advocacy services to persons using a service and their carers, including situations where the person may wish to make a formal complaint.

In addition to this, Alzheimer Scotland is strongly of the view that the legislation and any statutory guidance must be explicit that in cases where the person affected by an adverse event lacks mental capacity, those who hold power of attorney must be informed being informed. Moreover, the legislation must be explicit in defining the position of next of kin and carers and how the legal obligations of disclosure are to be met in those respects under the legislation.

Definition of a Disclosable Event

Alzheimer Scotland is clear that the proposals put forward must be considered within the current rights-based approaches to dementia care which emphasise the importance of maintaining personal autonomy wherever possible. As part of this, health and social care professionals are expected to adhere to best practice which allows and encourages a certain degree of considered risk-taking.

It must be recognised and factored into any 'candour' proposals that the individual using a service, their carers and professionals may have divergent views on the level of autonomy that a person may exercise, particularly where risk of harm or injury may be a factor. This

has the potential to make the identification of an adverse event highly contestable or subjective.

Alzheimer Scotland nevertheless broadly agrees that the definition for a 'disclosable event' should articulate that the event was:

'[An] unintended or unexpected event that occurred or was suspected to have occurred that resulted in death, injury or prolonged physical or psychological harm being experienced by a user of health and/or social care services'.

We further agree with the additional proposals detailing different circumstances under which an event would be deemed to be disclosable. However, we believe that section 9.12, *'returns to surgery, an unplanned re-admission to hospital, a prolonged episode of care, extra time in hospital or as an out-patient, cancellation of treatment or transfer to intensive care'*, is overly inclusive and could result in significant issues around decision-making disclosure, particularly in the context of delayed discharges, hospital acquired infections and other cases which may be open to interpretation around the requirement for disclosure. These are purely organisational and should be dealt with accordingly through other means.

Section 9.13, *'prolonged pain and prolonged psychological harm also needs to be taken into account when framing definitions (e.g. prolongation for a continuous period of 28 days)'* is problematic. Both pain and psychological distress in people with dementia can often be difficult to identify or quantify, are usually multifactorial and complex. Interpretation, particularly in relation to cause, can therefore be highly contentious.

Furthermore, Alzheimer Scotland believes that any accompanying statutory guidance must also set out who within the organisation or within individual services is responsible and accountable for making decisions about when an 'adverse event' has occurred and must be reported on. In addition to this, to support the clear decision-making processes within services, consideration should be given to a definition around 'suspected adverse events' and how these may be identified.

Reporting on Disclosable Events

Alzheimer Scotland supports the proposals as set out for the disclosure and reporting on adverse incidents, including the requirement for quarterly reporting.

As noted above, there is a need for clarity around what constitutes an 'adverse event' and subsequently what must be reported on. Accordingly, any accompanying statutory guidance should set out clearly the expectations upon services on what must be reported on and the manner in which this should be done.

In addition, although sections 7.1-7.3 set out that organisations must report publicly and submitted to a 'relevant organisation' (Alzheimer Scotland assumes that this refers to specific regulators and the commissioner of services, such as a local authority, health board or health and social care partnership – although it is not stated), it is not noted where this information will be publicly accessible. Therefore, it is crucial that the Scottish Government

ensures that people who use services, their families and carers are aware of this statutory duty of candour and the reporting mechanisms which accompany it. To ensure transparency and openness:

- It must be made clear where this information sits and how it can be accessed.
- The information must be made available in a range of formats.

As this information will be subject to public access, there will need to be a robust process in place that ensures confidentiality of all parties affected and we believe there is merit in a similar to the reporting mechanism of the Scottish Public Services Ombudsman which would allow for improvements in practice.

Monitoring of the statutory duty of candour

Alzheimer Scotland believes that it is appropriate that the current regulatory bodies should enforce this statutory duty of candour. However, it is imperative that regulators, when considering how to include this within their methodologies, consider both how enforcement will be approached during inspections and how to support services evidence their compliance with the statutory duty.

As noted within section 2.4 of the consultation document, the addition of this statutory duty of candour as part of the regulatory framework in England has resulted in a number of new enforcement powers, including civil penalties and criminal proceedings for organisations who repeatedly fail to adhere. It would seem appropriate that consideration should be given to regulatory bodies in Scotland receiving similar powers to address non-compliance in Scotland, in addition to existing powers including limiting new admissions or lowering of grades.

It should be open to all health and social care staff within respective settings, relevant social work staff and external regulatory bodies to initiate a formal incident review. However, it is crucial that a person who has experienced an adverse event, those with power of attorney or guardianship and carers should have the right to request a review, with a requirement to report all such requests that are declined to the relevant monitoring body, with a requirement for the request and the reasons for refusal to be documented. In addition to the suggested strengthening of the regulatory regime, it would be of value if the relevant regulatory body were able to investigate these cases, including refusals.

Alzheimer Scotland also considers it imperative that the number of disclosures is considered in the context of services' actions to improve and avoid future adverse events. In addition, it must be considered by regulatory bodies that high incidence of reporting on adverse events is not indicative of an above average number of adverse events, but may reflect a strong and well-adhered disclosure policy. The implementation of any legislation and accompanying statutory guidance should emphasise this point to ensure that people who use services, their families and carers can have confidence in the health and social care services.

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