

Adults with Incapacity Amendment Act Consultation

Scottish Government

October 2024

About Us

Age Scotland is the national charity for older people. We work to improve the lives of people over 50 and promote their rights and interests. We help older people to be as well as they can be, we promote positive views of ageing and later life, and we tackle loneliness and isolation. About Dementia is Age Scotland's dementia policy and practice forum. We work to ensure that the voices of people living with dementia and unpaid carers are heard at a policy level by building our policy responses with the voice of lived experience at the core.

About this call for views

We welcome the opportunity to respond to this consultation on the proposals to reform the Adults with Incapacity (Scotland) Act (2000), from now on referred to as the AWI Act throughout our response.

We believe that this consultation on the proposed amendments to the AWI Act is of particular importance for the people Age Scotland and About Dementia support. For example, the largest group of those individuals who lose capacity, and therefore may experience actions under the AWI Act being taken on their behalf, are those who lose capacity due to dementia.¹ With most people living with dementia being aged over 50, with approximately 87,000 people in Scotland over the age of 65 living with dementia,² legislation impacting these individuals must be fit for purpose and support the fulfilment of their human rights.

Whilst we acknowledge that a large proportion of those who are affected by incapacity legislation are those living with a dementia diagnosis, a key aim of About Dementia is around changing the narrative of the ability of individuals with a dementia diagnosis to make decisions. A stigma currently remains that as soon as a dementia diagnosis is received, that equates to someone not being able to make decisions like they once were able to. We believe this needs to change and will explore further in our response how supported decision making should be implemented to support those living with dementia to be actively involved in decisions were possible.

¹ Scottish Law Commission (2012). *Discussion Paper on Adults with Incapacity*.

https://www.scotlawcom.gov.uk/files/5813/4365/8223/DP_on_Adults_with_Incapacity_DP_156.pdf

² Scottish Government Website. *Mental Health: Dementia*. <https://www.gov.scot/policies/mental-health/dementia/>

What we have done to inform our response and our approach

The voices of older people and people affected by dementia are at the heart of our consultation responses. To inform this response, we focused on engaging with people affected by dementia as this is a key group of people who would be impacted by any amendments to the AWI Act. We felt it was important to engage with not only those living with dementia, but also those around them including carers and those potentially appointed as power of attorneys as they also need radical change to incapacity legislation to bring it in line with human rights conventions.

We carried out the following sessions to inform our response:

- 2 x In-person engagement sessions at peer-support groups for people affected by dementia in Fife. In total, we engaged with **26 individuals with lived experience**, with around **10 individuals** who were **living with dementia**.
 - For these sessions, we used a storytelling approach to enable us to have open conversations with the groups into a variety of topics related to the AWI consultation including power of attorney, training, guardianship orders and authority to research. More information about our storytelling resource can be found at <https://www.agescotland.org.uk/our-impact/about-dementia/publications-and-resources/storytelling-resource>.
- Online Policy Drop-In session attended by **four people** with lived experience of a dementia diagnosis or being a current or former unpaid carer for someone living with dementia.

We would like to thank the groups we visited for welcoming us along to their sessions and those who engaged with us online, for sharing their thoughts and personal experiences to help inform our response to this consultation.

Accessibility concerns with this consultation

The engagement we carried out to help inform our response raised some concerns with this consultation process. Firstly, there was a feeling that this consultation remained quite inaccessible, especially for those who may be most impacted by potential changes including people living with dementia and unpaid carers. We acknowledge that the Scottish Government has published an easy read version of the consultation document, however, for those who wish to respond in full, the complexity of the suggested changes and the overwhelming size of the 99-question consultation was seen by many as intimidating and exclusionary. We suggest that for future consultations, where possible there should be a shortened, more accessible response option, such as a short survey focusing on the key points most relevant to those with lived experience to provide an additional opportunity for gathering insights.

Organisations supporting those with lived experience, like Age Scotland and About Dementia, can help to bridge this gap with our specialist knowledge and we appreciate the context provided within the consultation document. However, we are aware that the opinions we have heard are not necessarily representative of how all those living with dementia, their unpaid carers or others potentially affected by the AWI Act will feel. Through our engagement what became apparent was the inextricable link between the Adults with Incapacity Act and a

person's fundamental human rights. There were concerns from some that some of the proposed amendments do not go far enough to protect the human rights of those who are deemed to not have capacity. Whilst we acknowledge that from a legislative point of view, these finer amendments are needed to increase clarity, safeguarding and/or streamlining processes, fundamentally improving the experience of the person at the centre of all decisions must be the main priority.

Principles of the legislation

1. Do you agree that the principles of the AWI Act should be updated to require all practicable steps to be taken to ascertain the will and preferences of the adult before any action is taken under the AWI Act?

Yes, we agree with this proposal. We believe that putting the will and preferences of an adult with incapacity at the centre of decision making will bring the AWI Act closer in line with the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

Through About Dementia's work over the past 5 years, we are aware of the stigma that commonly prevails in terms of someone who lives with a dementia diagnosis' ability to make decisions. This stigma must be addressed if the principles of the AWI Act are updated as suggested to ascertain the will and preference of individuals. People living with a dementia diagnosis still have will and preferences and with the correct support, these should be ascertained before any action under the Act is taken.

2. Do you agree that in the AWI Act we should talk about finding out what that adult's will and preferences are instead of their wishes and feelings?

We tentatively agree with this proposal. We believe that "wishes and feelings" is more subjective terminology and could therefore result in these being more likely to be dismissed, especially if an individual does not have someone they trust to advocate for them.

As an organisation, we accept the need for minor word changes as part of legislative change. However, we do feel it is important to highlight some of the frustrations raised by those with lived experience we spoke with in response to this proposed amendment. There was a feeling amongst some that this consultation was focusing too much on the semantics of the legislation, as opposed to the actual substance of practical changes to the way adults with incapacity are supported.

As one individual stated:

"A lot of these policy statements are just words, it's how you interpret these words really"

- Unpaid Carer

Additionally, one person living with dementia we engaged with said, ***"I don't think it makes it any clearer. What does 'will' mean?"*** Therefore, we urge that if this proposed change of terminology was to proceed, suitable guidance is created and circulated. This must include raising awareness of what is meant by 'will and preference', and how to go about ascertaining this from an individual who has limited or declining capacity. This should include clear examples of what someone's will and preferences are and how those in roles such as attorneys can take

all practical steps to ascertain this. Without clear guidance, ascertaining an individual's will and preference could remain an abstract concept that is not delivered in practice. Additionally, we believe further clarity should be provided within legislation and guidance as to how an individual's former will and preference (before they lost capacity) interacts with any current will and expressed. This should explain which of the will and preferences should be taken forward and enacted, especially if what is expressed is different. An example of this might look like an individual living with dementia stating that they are happy to go into residential care when required before they lost capacity, but clearly articulate later when their capacity may have declined, that they do not wish to do so. A situation like this may cause potential confusion for an attorney when they are unsure what the true will and preferences are of the individual in question.

3. Do you agree that any intervention under the AWI Act should be in accordance with the adult's rights, will and preferences unless not to do so would be impossible in reality?

Yes, we strongly agree with this proposal. With the correct guidance in place for those supporting adults with impaired capacity, it should always be possible to support individuals to exercise their legal capacity (their ability to make decisions and hold rights). Whilst there may be some situations where this is deemed "impossible in reality", we urge caution that this is only used in the most challenging of cases and not used as an excuse to avoid putting in effort and support to help individuals express their will and preference.

From our work across Age Scotland and About Dementia, we are aware of situations whereby capacity assessments can often not be carried out to their full potential and can be felt by some to be designed to determine incapacity, rather than to discover the 'will and preference' of an individual. As previously mentioned, what needs to change over and above amending the principles of the AWI Act, is the wider understanding of capacity, especially for people living with dementia, and how this is subjective and time dependent. Assessments need to ascertain will and preference, instead of looking to determine incapacity.

Supported Decision Making

4. Do you agree that the principles should be amended to provide that all support to enable a person to make their own decisions should be given, and shown to have been unsuccessful, before interventions can be made under the AWI Act?

Yes, we generally agree with this proposal.

We understand supported decision making to be the support for someone to exercise their legal capacity, rather than simply supporting someone to express a preference for someone else to consider (e.g., an attorney). Supported Decision Making (SDM) is something we believe to be important throughout life but can be especially helpful for those in later life, including when someone is living with a dementia diagnosis. SDM, if used properly, can help to promote a human rights-based approach to decision making, placing the person at the centre. The current system over-relies on the use of pre-appointed substitute decision making through schemes including power of attorney or guardianship orders. Whilst we support and acknowledge the importance of power of attorneys, especially for people living with dementia, we urge the Scottish Government to implement Supported Decision Making into Scots Law.

Supported Decision-making can be especially important for people living with dementia. Research, whilst still in its early days, has begun to look at specific strategies for SDM that can help those living with dementia to exercise their legal capacity. These include providing clear, accessible information about how to safeguard people living with dementia, the importance of building trusting relationships, adapting information to suit the needs of the person living with dementia and using flexible timescales for decision making.³ Another approach which might help people engage with SDM for those living with dementia, is a more flexible ‘spectrum approach’. This keeps SDM at the forefront but allows for increasing support as dementia progresses.⁴

For SDM to be implemented correctly for those with impaired decision-making capacity, we feel there needs to be greater clarity and awareness of exactly what supported decision-making is, and how to go about doing it. Firstly, as is stated in the Mental Welfare Commission’s Good Practice Guide for Supported Decision Making (updated in October 2024), varying interpretations and uses of SDM are common. We support their definition that SDM refers to “any process in which an individual is provided with as much support as they need in order for them to be able to make a decision for themselves and/or express their will and preferences within the context of substitute decision making”.⁵ Resources like the Mental Welfare Commission’s good practice guide are essential for a change in principles of the AWI Act to be realised in practice. We would urge that a shorter, more accessible guide or framework is created, co-produced by people with lived experience, and made readily available for those supporting someone with impaired capacity, including those living with dementia. This should include examples, like those that exist in the Mental Welfare Guide, at the forefront so that people can gain an understanding of what SDM looks like in practice. These guides must also include best practice in terms of respecting an individual’s identity, for example, their preferred pronouns, and cultural or religious beliefs.

From the insights gathered to inform our response, there was a sense amongst some who care for an adult with a dementia diagnosis, that they already engage with supported decision making. There was a sense amongst others that this could make things more complicated, bureaucratic and result in more paperwork; something which carers are already overwhelmed by. We urge the Scottish Government to think about this when considering how to ensure SDM is followed and that it does not increase burden on those who already use SDM throughout their daily lives.

Having participated in the stakeholder group and roundtable discussions facilitated by the Scottish Commission for People with Learning Disabilities, we agree with the consensus amongst this group that for updated principles of the AWI surrounding the use of SDM to be followed, there needs to be a national framework for SDM, potentially building on the existing framework

³ Dixon, J., Donnelly, S., Campbell, J., & Laing, J. (2021). ‘Safeguarding People Living with Dementia: How Social Workers Can Use Supported Decision-Making Strategies to Support the Human Rights of Individuals During Adult Safeguarding Enquires. *The British Journal of Social Work*. <https://doi.org/10.1093/bjsw/bcab119>

⁴ Sinclair, S., et al (2019). ‘A Real Bucket of Worms: Views of People living with Dementia and Family Members on Supported Decision-Making’. *Bioethical Inquiry*. <https://doi.org/10.1007/s11673-019-09945-x>

⁵ Mental Welfare Commission for Scotland (2024). *Support decision making Good practice guide*. <https://www.mwscot.org.uk/sites/default/files/2024-10/Supported%20Decision%20Making%202024.pdf>

created by People First.⁶ A framework could ensure that there are clear processes and accountability in place to ensure that SDM is realised in practice.

We have some concerns about the part of question 4 stating that individuals will have to show that all support has been “shown to be unsuccessful”. Including this within the principles of the AWI Act does not feel like the most productive approach to promote the use of supported decision-making as it could lead individuals to feel from the start that supported decision making is unlikely to be successful, they simply need to prove they have tried.

5. Do you agree that these principles should have precedence over the rest of the principles in the AWI Act?

Yes, we tend to support the idea that this principle should be one of the most important within the Act. However, we ask for caution that the other important principles of the AWI Act, such as the action being the minimum necessary and the least restrictive option, should not be neglected.

6. Do you have any suggestions for additional steps that could be put in place to ensure the principles of the AWI Act are followed in relation to any intervention under the Act?

Firstly, there is the need for further training for individuals working with adults with potentially impaired decision-making capacity and people in substitute decision-making roles. This training needs to be accessible, interactive and engaging. As previously mentioned, it must include clear examples of how to carry out supported decision making. Additionally, there needs to be more clarity about how the implementation of the AWI Act will be monitored and evaluated to provide insight into how it is being used and where any improvements need to be made.

Proposed terminology changes

7. Do you agree with the change of name for attorneys with financial authority only?

We broadly support this proposal as we agree that a change in terminology could help to reduce misunderstanding and confusion surrounding what different types of power of attorney's can be used for. Age Scotland offers information and advice services via our information guides and helpline. From this perspective, changing the name to a financial power of attorney would be helpful as with the way it currently stands, continuing power of attorney can be a confusing term, especially for people living with dementia.

During our in-person engagement sessions, the topic of power of attorney was front and centre. Encouragingly, most of the group said they had a power of attorney in place. However, when asked which type they had, there was some sense of confusion. Several stated they had both the ‘medical’ and financial’ one, with one individual explaining that these were the terms the lawyer had used when they were setting it up. When explaining the official names being welfare and continuing power of attorney, there was a consensus that renaming the continuing power of attorney to financial, was a sensible idea and that this would be helpful for both improving understanding and consistency, especially if professionals are already using this term.

⁶ People First Scotland (2019). *Supported Decision-Making A Framework*. <https://peoplefirstscotland.org/wp-content/uploads/2019/02/Framework-Final.compressed.pdf>

As a caveat to consider, during another engagement session some carers or former carers were adamantly against changing the name to a ‘financial’ power of attorney. As one carer explained, a continuing power of attorney is about so much more than just finances. This is true. A continuing power of attorney can also relate to property affairs, which also includes aspects such as any social media or email accounts.⁷ We are conscious that we are trying to express a range of views that are at times conflicting and from an organisational perspective, we agree this proposal will overall help to reduce confusion. However, before any changes are made, we suggest that full consideration is given to those with lived experience. Whether the change is accepted or not, we ask that further effort is made to make it clearer for users as to what different types of power of attorney’s cover and when they can be used. For instance, greater awareness is needed that a financial power of attorney can either take effect immediately or only once capacity is lost. A potential option to consider, could be to follow a line similar to in England and Wales. Instead of renaming it to a ‘financial’ power of attorney, it could be renamed as a ‘power of attorney for financial and property affairs’.

Sheriff’s power of directions

8. Do you agree with our proposals to extend the power of direction of the sheriff?

Yes, we agree with this proposal. We agree that extending the power of direction of the sheriff could help provide transparency and protection for an adult if there have been changes in their attorney or guardian.

Additionally, we also agree with the proposal to extend the power of Sheriff’s under section 3(3) of the AWI Act. If this proposal was passed, we would hope this would result in fewer instances of critical funds getting delayed and a more streamlined and efficient process.

Authority of the Public Guardian

9. Do you agree with our proposal to amend the powers of investigation of the OPG to enable, where appropriate, an investigation to be continued after the death of the adult?

We are generally in support of this proposal. If this is to be instigated, it is essential that the required funding and resources are allocated to the OPG to support this to avoid creating additional delays elsewhere in the organisation.

Investigations into cases under the Adults with Incapacity Act

10. Do you agree that the investigatory responsibility between OPG and local authority should be split in the manner outlined above?

Yes, we strongly support this proposal as we feel this will provide greater clarity of responsibilities and reduce duplication of effort and resources. We encourage a more joined up approach to investigations of cases, however, we ask that local authorities receive the resources they would need to take on these extra duties.

11. Will these changes provide greater clarity on the investigatory functions of OPG and local authority?

⁷ Sandra McDonald (2021). ‘Power of Attorney. All you need to know: granting it, using it or relying on it’.

Yes, see response to question 10 above. If this proposal is implemented, there must be clear and accessible information provided to the public and organisations as to where the first instance of concern should be raised.

12. Will this new structure improve the reporting of concerns?

Yes, we feel that this new structure could improve things but as mentioned in response to question 11, this will only happen if people are aware of where to go in the first instance. Additionally, there needs to be clear communication between the OPG and local authorities for referrals to be made if someone has not come to the correct organisation at first.

Powers of attorney

Training for attorneys

13. Do you agree with the proposals for training for attorneys?

In principle, we strongly support the need for training for attorneys. We often hear of experiences of attorney's feeling like they lack support to understand their role and what they need to do. Therefore, access to high quality training and straightforward to understand guides could help to ensure that those taking on this role understand what this will involve, how to execute their duties to a high standard and could help to avoid negligence

Whilst broadly in support, we feel that more clarity is required in terms of the level of detail this training will go into, how it would be implemented and monitored in practice and we ask for consideration to be given to the real-life experiences of those who take on the role of an attorney.

Firstly, in terms of overseeing mandatory training for all people appointed as attorneys, this feels like a huge challenge to control. As one unpaid carer we spoke to said:

"I don't know how on earth they are going to be able to police that and make sure that happens for thousands of people."

- Unpaid Carer

The proposal for the OPG to check if prospective attorneys have completed the training before they agree to take on the role adds potential delays to the system of registering a PoA which already faces lengthy backlogs. If implemented, it must be underpinned with appropriate resources to avoid impacting other areas of work.

Additionally, based on the insights from some of those with lived experience of being attorneys, another potential challenge of the proposed mandatory training is that it may be off-putting for certain groups of people to take on the role. For example, if only available online, this excludes a large proportion of the population of those who may become attorneys, including more vulnerable groups of older people and those living with disabilities.⁸ We are supportive of

⁸ Scottish Parliament (2024). *Public Audit Committee: Tackling digital exclusion*.
<https://www.parliament.scot/~media/committ/8754/Paper-1-Tackling-digital-exclusion#:~:text=It%20is%20estimated%20that%2015,secure%20access%20to%20the%20internet.>

training for attorneys being readily available and we ask for this should be offered both online and in-person, potentially in carers centres, so certain groups are not excluded.

Some carers we spoke with highlighted that making something mandatory could be seen as intimidating. Some felt it might add to the feeling of scrutiny and a 'blame culture' they feel accompanies the role of an attorney. Furthermore, whilst we acknowledge that training is very important, several unpaid carers we engaged with felt that having mandatory training for attorneys before appointment could put additional stress on the carers during an already demanding time, for example following a dementia diagnosis. A final potential issue of mandatory training raised by one of the groups of those with lived experience we engaged with was that if the unfortunate situation of someone in the position of attorney was intent on abusing this power, training would not help discourage this. We suggest that further considerations are made before mandatory training is introduced to ensure that these experiences of some people are properly considered.

Furthermore, alongside training, we suggest that information and advice for those appointed as attorneys is also improved in terms of usefulness and accessibility. For example, several of the people we engaged with mentioned that instead of regimented training, advice and information are of more use and less intimidating. For example, this could include a dedicated power of attorney helpline run by the OPG, specific to providing advice for those appointed as attorneys.

Enhancing the safeguards around power of attorney

14. Do you agree that the Office of the Public Guardian should be given power to call for capacity evidence and defer registration of a power of attorney where there is a dispute about the possible competency of a power of attorney document?

We tentatively agree with this proposal. Safeguarding individuals is of upmost importance and if there is doubt around the capacity of the granter, especially if there are any concerns of their understanding of what powers they are granting and to who, we agree that there needs to be measures to address this. However, if additional powers are given to the Office of the Public Guardian, there must be sufficient resourcing provided to allow these additional checks to be carried out, without adding further delays to registering other power of attorney documents. There currently remains a significant backlog within the OPG for registering PoA applications. As of October 2024, PoA are being processed from as far back as December 2023; a 10-month delay.⁹ This urgently needs addressing and any additional powers given to the OPG must not exacerbate this issue further.

15. Do you agree that the Office of the Public Guardian should be able to request further information on capacity evidence to satisfy themselves that the revocation process has been properly met?

Yes, we tend to support this proposal. See above response to question 14.

⁹ Office of the Public Guardian (Scotland). <https://www.publicguardian-scotland.gov.uk/general/news/2024/10/07/poas-to-be-processed-this-week>

16. Do you agree that OPG should be given the power to determine whether they need to supervise an attorney, give directions or suspend an attorney on cause shown after an investigation rather than needing a court order?

One of the key concerns raised by some of those we engaged with was around the scrutiny and ‘blame game’ felt by many who are appointed as attorneys. Whilst this proposal and others within the consultation we understand are for situations where serious concerns are raised, and that the OPG would not have this power over all attorneys, we urge that any changes are communicated and exercised with caution to avoid increasing a sense of scrutiny and blame. One individual we spoke to explained how often there is a lack of awareness of how much you give up being an attorney.

“I would think twice about being a power of attorney for anybody again [...] you get scrutinised, there’s a blame culture [...], you give up so much of your own life.”

- Unpaid Carer

What ultimately needs to change, alongside the amendments to the AWI Act to enhance the safeguards around power of attorneys, is the attitudes and perceptions of those carrying out these vital roles. We need more people in Scotland to have a power of attorney in place but unless the culture and feelings of those who take on these roles are addressed, this will not happen.

Increasing accessibility of powers of attorney

17. Should we extend the class of persons that can certify a granter’s capacity in a power of attorney?

We tend to support this proposal; however, we present several points for consideration. We can see how widening the pool of those who can grant capacity could help to increase the uptake of power of attorney which we are ultimately in support of. However, echoing the concerns raised in our response to the consultation on the AWI Act in 2018, we are aware of potential concerns of how capacity is assessed. The example used here concerned solicitors, who currently under the AWI Act can certify someone’s capacity when creating a power of attorney, not appearing to have sufficient training or expertise to carry out this task. Therefore, in response to the suggestion of adding paralegals and clinical psychologists to the list of those who can grant capacity, we are tentatively supportive, so long as the correct training, supervision and auditing is provided consistently and to a high quality across Scotland.

We feel that this is especially important in relation to assessing a granter’s capacity if they have a dementia diagnosis. As previously mentioned, just because someone receives a dementia diagnosis, despite the stigma that persists amongst some, does not mean the individual is immediately incapacitated. It is paramount that those assessing a granter’s capacity are aware that for people living with dementia, capacity is not a black or white concept and can be subjective and time dependent. The complexities and nuances of this must be made aware to any person who has the authority to certify a granter’s capacity, both for those with the powers now and any persons potentially added to the class.

18. Do you agree that a paralegal should be able to certify a granter's capacity in a power of attorney?

See above answer to question 17.

19. Do you agree that a clinical psychologist should be able to certify a granter's capacity in a power of attorney?

See above answer to question 17.

20. Which other professionals can certify a granter's capacity in a power of attorney?

No comment

21. Do you agree that attorneys, interveners and withdrawers (under Part 3) should have to comply with an order or demand made by OPG in relation to property and financial affairs in the same way as guardians?

We somewhat agree with this proposal but echo previously mentioned caveats that need to be considered. These include the increased demand for the OPG this could create, with a need to back any additional powers with appropriate funding and resources.

Broadening powers of Public Guardian to order compliance with demands in relation to property and financial affairs of the adult

22. Do you agree that the Public Guardian should have broader powers to suspend powers granted to a proxy under the AWI Act whilst an investigation is undertaken into property and financial affairs?

Yes, we tend to agree with this proposal as the current situation means that financial harm could occur if the proxy is able to undertake property and financial affairs while an investigation is ongoing. However, we ask this should be taken in a proportionate approach so that the individual's financial needs are not unduly impacted. Additionally, if this were to happen, the adult with incapacity must be aware of the situation and accessible information and support must be provided to them. We also ask that appropriate levels of sensitivity are applied when an investigation is made, to avoid contributing to a blame culture, especially in cases where a proxy is found innocent.

23. Do you agree that the MWC and local authority should have broader powers to suspend powers granted to a proxy under the AWI Act whilst they undertake an investigation into welfare affairs?

Yes, we agree with the proposal. See response to question 22 above. Furthermore, if these powers are broadened for the MWC, local authorities and the Public Guardian, these organisations need to be cautious of any malicious complaints, before powers are suspended.

Access to Funds

24. Do you agree that the powers and specific amounts should be decoupled?

Yes, we generally agree with this proposal regarding the Access to Funds (ATF) scheme run by the OPG. We are supportive of any changes that create a more streamlined process for those

who are using this scheme. For example, removing the need to apply to the OPG every time for instance a direct debit amount needs changing, could help to reduce the burden on these individuals.

25. Do you agree that the withdrawal certificate should contain standard, proforma powers for the withdrawer to use?

We tend to agree with this proposal based on the points mentioned in response to question 24. Additionally, we support the proposal in the consultation document to allow for the withdrawal certificate to allow for a range of actions, including the ‘administration and disbursement of fund for self-directed support’. It is widely known that self-directed support (SDS), despite significant potential, is not used in practice as required despite being a potentially useful mechanism to deliver social care. Having this as a listed action on the withdrawal certificate could enable SDS to be continued to be used following someone losing capacity to make these decisions, with it remaining that the will and preference of the individual is still ascertained and followed using supported decision-making principles.

26. Do you agree that access should be given to the adult’s current account, rather than setting up a ‘designated account’?

We tend to agree with this proposal. If providing access to the adult’s current account creates a clearer and more consistent system, then this seems like a good suggestion. More detail however is needed as to how the OPGs supervision would offset any of the risks associated with this change as this currently seems quite vague.

27. Do you agree that in certain circumstances, applications where there is a guardian, or intervener with powers relating to the funds in question should be allowed?

Yes, we tend to support this proposal based on the examples outlined in the consultation if it will make the flow of necessary funds simpler, whilst still maintaining accountability.

28. Do you agree that we should clarify that a bar to applying under this section only applies if someone is already authorised under Part 3 of the Act to intromit with the same funds?

Yes, we support any clarification which can be provided for those using the ATF scheme under the AWI Act to make the process as understandable and accessible as possible.

29. Does having an account in the adult’s sole name limit organisational use of the scheme?
No comment.

30. Should we add the same transition provisions to intervention orders as there are for guardianships?

No comment.

31. Do you agree that sheriffs, under certain circumstances, should be able to grant powers to access funds under our new proposal?

Yes, we agree with this proposal. If this change allows for the ATF scheme to be used, if this is the most appropriate intervention, then it seems sensible and in line with the overall principles of

the AWI Act. Additionally, any steps to prevent delays in applications seem reasonable, as long as only in specific and relevant circumstances.

32. Do you agree that authorised establishments should be able to apply under the ATF scheme?

We are unsure about this proposal and do not think there is sufficient explanation in the consultations as to why this is needed. Allowing authorised establishments, including care home services, to apply under the ATF scheme feels like a conflict of interest. If these establishments are potential beneficiaries of funds, such as private care homes, it is concerning that they might be able to directly access funds. This feels open to the potential for misuse, however underused it is.

33. Do you agree we should split intimation of the application between organisations and lay people (OPG)?

Yes, we agree with this proposal.

Management of residents' finances

34. Do you support the proposal to remove Part 4 from the AWI Act?

We do not hold a strong view on this proposal. If part 4 is not commonly used, we can see why removing this section of the AWI Act would make sense. However, as mentioned in our response to question 32, we are reluctant to support the proposal to allow authorised establishments to apply under the ATF scheme as an alternative to part 4 if removed.

For adults who lived in 'authorised establishments' such as care homes, where most residents deemed as having incapacity is likely due to dementia, allowing managers to access the finances on their behalf feels like a conflict of interest. We acknowledge that this is a rarely occurring case, only required in the most complex of situations and is currently supervised by the Care Inspectorate, Healthcare Improvement Scotland and the State Hospital Board. However, removing the option feels like the safest option. What is needed is further work to ensure that power of attorney uptake is increased to prevent the need for authorised establishments to access the finances of residents.

35. Do you think alternative mechanisms like the ATF scheme, guardianships and intervention orders adequately address the financial needs of adults with incapacity living in residential care settings and hospitals?

We tend to agree with this statement. However, as stated in our response to questions 32 and 34, we remain concerned about the potential of people with a financial stake having control over an adult with incapacity's funds.

Changes to s47 certificates and associated matters

36. Do you agree that the existing section 47 certificate should be adapted to allow for the removal of an adult to hospital for the treatment of a physical illness or diagnostic test where they appear to be unable to consent to admission?

We tentatively support the proposal for the changes to s.47 certificates but remain cautious about this. Firstly, if this proposal is accepted, the removal of an adult to hospital where they cannot consent to admission needs to be only in extreme, life-threatening circumstances. However, we are unsure if this is even relevant for a s.47 certificate as under ‘common law’ medical treatment can be given in an emergency, even without the individual’s consent, if for the preservation of life or prevention of serious deterioration.¹⁰

If this proposal was to be approved, steps need to be taken to ensure that wherever possible, the will and preference of the individual remains at the heart of the decision. As one individual we spoke with mentioned, this proposal feels at conflict with the idea of following someone’s will and preferences at all costs. We do not agree with the phrase ‘appears to be unable to consent to admission’. This implies that an initial perception that someone lacks capacity could be used to administer a s.47 certificate. This opens the door for instances like previously mentioned, where a simple diagnosis of dementia could be seen to some to equate to them not being able to consent, when in reality their capacity has not been properly understood. Instead, if accepted this should read as something along the lines of ‘where the capacity of the individual to make this decision appears impaired but following efforts to ascertain their will and preference, and consultation with any relevant proxy(s)’.

Concerns were also raised by those we engaged with on this topic about whether authorities could override the will and preferences of individuals or proxies, when situations are urgent. The example of the use of DNAR orders implemented during the pandemic without consulting with proxies or family members was highlighted. There was a concern that similar patterns of using an s.47 certificate to convey someone to hospital, in a situation where those closest to them might not be able to be contacted, could occur. It was felt by some that we engaged with that if the proposal to change the AWI Act was approved, there would need to be very strong and stringent safeguards in place to ensure that what the individual wants is at the centre of everything, and no action is taken which could be seen to as infringe on their human rights.

37. Do you consider anyone other than GPs, community nurses and paramedics being able to authorise a person to be conveyed to hospital? If so, who?

Other professionals who could potentially be able to authorise a person to be moved to hospital could include geriatricians, allied health professionals (AHPs) or social workers. If included, there must be appropriate training provided for these professionals, especially looking at the principles of supported decision making. Additionally, the use of advance directives and anticipatory care planning should also be encouraged as then these professionals might have a better idea of the individual’s wishes for the situation.

¹⁰ Mental Welfare Commission for Scotland (2021). *Treatment under section 47 of the Adults with Incapacity Act: overview and guidance. Good practice guide.* https://www.mwscot.org.uk/sites/default/files/2021-04/TreatmentUnderSection47oftheAdultsWithIncapacityAct_April2021.pdf

38. Do you agree that if the adult contests their stay after arriving in hospital that they should be assisted to appeal this?

Yes, we support that if the amendment s.47 certificate was to be used, an adult who contests their stay in hospital should be assisted to appeal this if they have the capacity to do so. Independent advocates play a vital role in ensuring that someone's human rights are met. If someone is contesting to being taken to hospital, if against their expressed will and preference, they should be supported to appeal this decision if they require additional support. However, there must be consideration to avoid an environment where healthcare professionals do not want to convey people to hospital out of fear of appeals or complaints being created.

39. Who could be responsible for assisting the adult in appealing this in hospital?

No comment.

40. Do you agree that the lead medical practitioner responsible for authorising the section 47 certificate can also then authorise measures to prevent the adult from leaving the hospital?

No comment.

41. Do you think the certificate should provide for an end date which allows an adult to leave the hospital after treatment for a physical illness has ended?

No comment.

42. Do you think that there should be a second medical practitioner (i.e. one that has not certified the section 47 certificate treatment) authorising the measures to prevent an adult from leaving the hospital?

No comment.

43. If yes, should they only be involved if relevant others such as family, guardian or attorney dispute the placement in hospital?

No comment.

44. Do you agree that there should be a review process after 28 days to ensure that the patient still needs to be made subject to the restriction measures under the new provisions?

No comment.

45. Do you agree that the lead clinician can only authorise renewal after review up to maximum of 3 months before Sheriff Court needs to be involved in review of the detention?

No comment.

46. What sort of support should be provided to enable the adult to appeal treatment and restriction measures?

There must be a system in place to ensure that all possible support is provided to an adult with incapacity to appeal treatment and restriction measures in line with human rights conventions. This should include using principles of supported decision-making to help individuals understand why certain treatments or restrictions might be potentially necessary in a way that is accessible to them. This should not be a one-off attempt, where if deemed as ‘unsuccessful’ it is simply a tick in a box to then not try again. Furthermore, independent advocacy services, including specialist advocates trained for supporting people with conditions such as dementia should be available to all those wishing to appeal any treatment or restriction, and this should be clearly advertised to the individual.

47. Do you agree that section 50(7) should be amended to allow treatment to alleviate serious suffering on the part of the patient?

Yes, we agree with this proposal.

48. Would this provide clarity in the legislation for medical practitioners?

Yes, we hope that this would provide extra clarity for medical practitioners.

Changes to guardianship, interim guardianship and intervention orders

Medical reports

49. Do you think the requirement for medical reports for guardianship order should change to a single medical report?

We tentatively agree with the proposal to change the requirement to a single medical report for a guardianship order instead of the current requirement for both a GP and psychiatrist report. We are supportive of any measures that could help to speed up the process of guardianship orders being processed, especially in cases where an individual may not be able to be discharged from acute hospital settings until an order is in place, potentially leading to a deterioration in their mental and or physical health. With the proportion of guardianship orders granted after more the six months for individuals with a primary diagnosis of dementia increasing,¹¹ it is important that these waits are brought down.

We acknowledge that the consultation sets out that clear guidance will be provided so that the person writing the report (either a psychiatrist or GP), is aware of what is required. Whilst this is important, and we support making processes more streamlined and efficient, we ask that this change is approached with caution to ensure that all safeguards are met. With a dementia diagnosis being the second most common diagnosis for needing a guardianship order, and this cause of incapacity presenting potentially unique challenges in how it is assessed, if this proposed change was accepted, steps must be taken to ensure that this would not have a detrimental impact on those living with dementia if they needed a guardianship order granted.

An alternative option to completely remove the requirement for a second report could be to have a single report but verified by a second medical opinion to ensure that there is an agreement.

¹¹ Mental Welfare Commission Scotland (2024). *Adults with Incapacity Act monitoring report 2023-24*. <https://www.mwscot.org.uk/sites/default/files/2024-09/AWI%20Monitoring%20Report%202023-24.pdf>

50. Do you agree with our suggestion that clinical psychologists should be added to the category of professional who can provide these reports (where the incapacity arises by reason of mental disorder)?

As previously stated, we support measures to increase the efficiency of the process of granting guardianship orders. Echoing our earlier response to question 17, it is vital to ensure that all appropriate professionals have the correct training, support and awareness of conditions which might impact capacity.

If clinical psychologists were to be added to the list of professionals who can provide a medical report for a guardianship application, we feel there needs to be further clarity on who they can provide these reports for. The consultation states that this would be for guardianship cases where incapacity is by reason of mental disorder. If this amendment did happen, there must be clarification as to whether people with a diagnosis of dementia are included within this scope. Whilst dementia is not explicitly stated under the definition of 'mental disorder' in section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003, the act is still often used against individuals living with dementia. We acknowledge that there is ongoing work on the definition of mental disorder outwith the scope of this consultation. However, if clinical psychologists were to be added to the list of those who could complete medical reports, where incapacity is due to 'mental disorder' there must be explicit guidance on if this includes when incapacity is caused by dementia to reduce any potential for misunderstanding.

Mental Health Officer & Person with Sufficient Knowledge reports

51. Do you think the Mental Health Officer form for guardianships can be improved, to make it more concise whilst retaining the same information?

We do not hold a strong view on this as we are not the ones completing these forms.

We reiterate that we are supportive of streamlining and improving the efficiency of the guardianship application process, especially with the large number of orders which are put in place for people with a dementia diagnosis (35% of orders in 2023/24).¹² Despite needing to address delays in the process, the most important aspect throughout should remain the needs and preferences of the individual. One aspect of this is obtaining the views of those nearest to the individual and we would urge for this to continue. As to if and how the report can be more concise, whilst retaining the same information, having not completed an MHO officer report this is difficult to determine, yet on the surface, it does seem contradictory to make something more concise without losing important information.

52. Do you think the 'person with sufficient knowledge' form can be improved, making it more concise whilst retaining the same information?

See comments above in question 51.

One comment which arose from our engagement with those with lived experience of dementia was around the complexity of guardianship orders. They questioned the vagueness and subjective nature of who can complete a 'person with sufficient knowledge' form. It was seen by

¹² Mental Welfare Commission Scotland (2024). *Adults with Incapacity Act monitoring report 2023-24*. <https://www.mwscot.org.uk/sites/default/files/2024-09/AWI%20Monitoring%20Report%202023-24.pdf>

some as an unnecessary case of bureaucratic exercise, requiring over justification for decisions and adding complexity to guardianship applications, which are already complicated enough.

53. Should the person with sufficient interest continue to be the person who prepares the report for financial and property guardianship?

No comment.

54. Do you agree with our proposal to replace the second part of the ‘person with sufficient knowledge’ report with a statutory requirement to complete the OPG guardian declaration form?

We somewhat agree with this proposal if this would help to reduce duplication of information. However, in doing so, we raise the question of if the ‘person with sufficient knowledge’ report would still be necessary, if the second part was replaced with the OPG Guardian declaration form. With the remaining part of the report being the section on the appropriateness of the order, we ask if this could not also be incorporated into the OPG guardian declaration form as perhaps a section specifically asking an individual deemed to have sufficient knowledge to comment on the appropriateness of the order. This would help to streamline and reduce the complexity of guardianship applications for those who may have lots of contending issues to deal with, such as a loved one being stuck in hospital.

Sheriff discretion to consider MHO Report out with 30 days limit

55. Should sheriffs be afforded the same discretion with mental health officer report timings as they are with medical reports?

Yes, we agree with this proposal. Bringing the same discretion for MHO reports as for medical reports seems appropriate and we support a change to reduce potential delays where the report is just over the current 30-day limit. We do ask that there is still a limit to prevent any significant changes having occurred since the report being written and the sheriff’s consideration.

Amendment of interim guardianship order for urgent cases

56. Do you agree that the best approach to cater for urgent situations is to amend the existing interim guardianship orders?

On principle, we agree with the proposal to amend existing interim guardianship orders. The current situation of needing to make a full guardianship order application to ask for interim powers creates an unnecessary long process. Allowing interim guardianship to be applied for separately when a situation is urgent seems like a sensible suggestion.

We do, however, have some concerns. Some of the people we engaged were worried about the complexity this might add to the application process. It was felt that adding another layer could create more confusion about what the correct order to apply for is, consequently creating more barriers to receiving the correct care. There was a sense that the layers to guardianship orders makes it more difficult for both carers who may be apply for guardianship orders, and the people with incapacity during a very difficult time. Whilst we agree with the need to reform guardianship to be able to be used in urgent situations seems necessary, it needs to be done in a

way that is simple to understand, does not increase the complexity of the application process and follows a human-rights based approach

Furthermore, there needs to be an effort to increase the uptake of power of attorney, so that if urgent situations arise, decisions can be made quickly without the need to apply for guardianship orders. There must be a concerted effort from the Scottish Government to address some of the fundamental underlying barriers to accessing a power of attorney including importantly the cost as we will discuss later in response to question 88.

57. Do you agree that an abbreviated mental health officer report together with a single medical report should suffice for a guardianship order to be accepted by the court in the first instance?

If the proposal to amend existing interim orders is accepted, then we tend to agree with the proposal for an abbreviated MHO report with a single medical report. We strongly agree that if this were to be approved, the MHO report should still demonstrate how the principles of the AWI Act have been followed. We feel that if this proposal was introduced, it must be carefully and closely monitored to ensure that it is working and there is sufficient safeguarding still in place. Furthermore, from one person living with dementia we engaged with, they stated that they felt that a mental health officer did not necessarily have the expertise needed for this process, and perhaps social workers would be better placed.

58. Do you agree that there should be a short statutory timescale for the court to consider urgent interim applications of this sort?

Yes, we tend to agree with this proposal. In urgent situations, there needs to be a short timescale for applications to be considered for many reasons including to reduce stress on those awaiting decisions, and to prevent deterioration of someone's condition, for example if they are being delayed from being discharged from hospital. However, we urge that this is always balanced to ensure that due diligence into each individual case is carried out and not rushed unnecessarily.

Variation of guardianship order to add financial or welfare powers

59. Do you agree that further medical reports are not required when varying a guardianship to add either welfare or financial powers?

Yes, we agree with this proposal. The current system seems to have an unnecessary duplication of effort, adding delays. We are supportive of the proposal if it makes the process of adding either welfare or financial powers to an existing guardianship more efficient and removes layers of ineffective bureaucracy which is a consistent criticism of the guardianship system.

If accepted, we suggest that a period of monitoring is used to ensure that the individual with incapacity is still at the centre and the appropriate safeguards remain in place for urgent situations which might require quicker decisions.

Length of guardianship orders

60. Does the current approach to length of guardianship orders provide sufficient safeguards for the adult?

No comment.

61. Do changes require to be made to ensure an appropriate level of scrutiny for each guardianship order?

No comment.

62. Is there a need to remove discretion from the sheriff to grant indefinite guardianships?

We do not necessarily agree with the need to completely remove the discretion from the sheriff to grant indefinite guardianship orders. However, even if an order is deemed 'indefinite', there should remain regular periods of review to ensure that this order remains appropriate. Additionally, we think that a sufficient appeal mechanism is needed if there is a breakdown in relationship between the adults with incapacity and their guardian.

63. If you consider changes to be necessary, what do you suggest they would be?

No comment.

Adding additional exclusions to the AWI Act

64. We propose that the following powers should be added to the list of actions that guardians, attorneys and interveners should be expressly excluded from. Do you agree with this proposal?

The most striking finding from our engagement looking at this proposal, especially as the majority stated they already had a PoA in place, was the lack of knowledge that an attorney could currently make certain decisions on the granter's behalf. Our engagement raised several different views and remains inconclusive on if these powers should be excluded or not (see **Figure 1** below). However, as an organisation we broadly support the suggested actions being excluded from the powers an attorney, guardian or intervenor can take. We see these actions as extremely personal, and someone else making these on your behalf could be viewed as an infringement of their human rights. Withstanding any changes, we believe that there needs to be clearer information available when creating a power of attorney as to what powers an attorney might have unless otherwise stated within their power of attorney document.

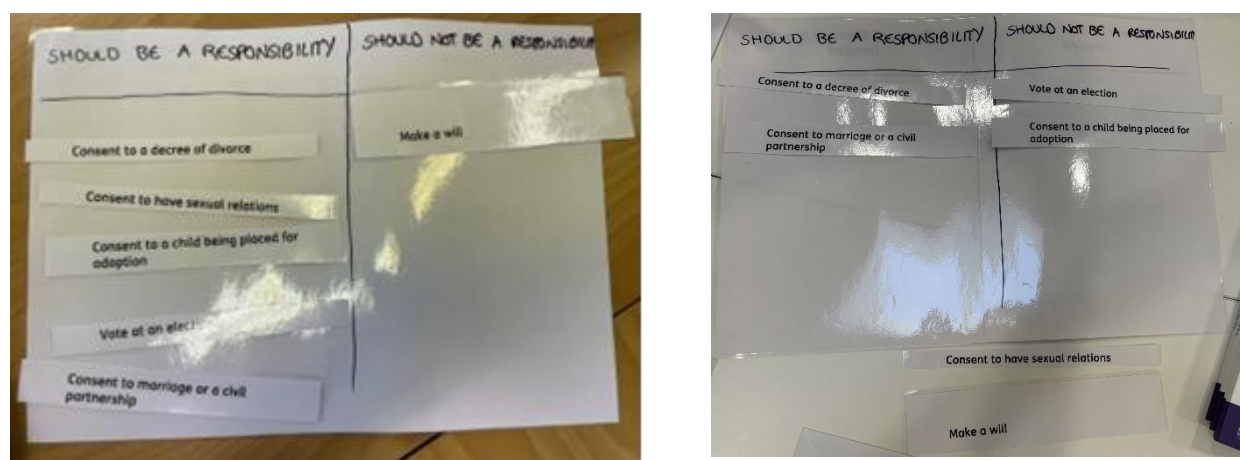


Figure 1 - Images of activity looking at if actions should be excluded from attorneys' powers

A) consenting to marriage or a civil partnership

Yes, exclude.

B) consenting to have sexual relations

Yes, exclude.

From those we spoke with, there was a clear hesitancy and uncertainty surround this action. Some highlighted that the nature of the relationship between attorney and granter might impact this decision, if this was to remain a power of a proxy decision maker. Additionally, several people raised the issue within the context of care homes where sexual relations are often discouraged, when they might not legally have the power to support.

C) consenting to a decree of divorce

Yes, exclude.

Some of those we spoke with noted that it was hard for them to think of situations not like their own. For example, a lot of those with lived experience in the groups we engaged with were power of attorneys for a partner, however, it was hard to put yourself in the shoes of someone who might be a power of attorney for a parent. When considering the exclusion of these actions, all dynamics should be considered by decision-makers.

D) consenting to a dissolution order being made in relation to a civil partnership

Yes, exclude.

E) consenting to a child being placed for adoption by an adoption agency

Yes, exclude.

F) consenting to the making of an adoption order

Yes, exclude.

G) voting at an election for any public office, or at a referendum

Yes, exclude.

Several people we consulted with mentioned how they had had discussions during recent elections with the person they cared for and whilst they supported the person living with dementia, they did not influence their final decision.

H) making a will

Yes, exclude.

I) if the adult is a trustee, executor or company director, carrying discretionary functions on behalf of them

Yes, exclude.

J) giving evidence in the form of a sworn affidavit

Yes, exclude.

65. Are there any other powers you think should be added to the list of exclusions?

We do not have any specific suggestions for other powers to be added to the list of exclusions. However, we suggest that the list of powers an attorney, guardian or intervenor can or explicitly cannot exercise must be made very clear to those involved during the process of creating a proxy decision-making document.

Deprivation of liberty proposals, stand-alone right of appeal and appointment of safeguarders

66. Do you agree with the overall approach we are proposing to address DOL?

Yes, from our understanding of the overall approach to DOL being proposed, we tend to support this. We support the proposal to include within the code of practice and guidance the factors which need to be considered when deciding if an adult will be subject to a deprivation or restriction on their liberty. We support the use of the term ‘deprivation of liberty’ within this guidance and legislation. However, we question if this term is well understood as is stated in the consultation document. If included, we feel the term ‘deprivation of liberty’ needs to be clearly defined in a way that is accessible for everyone to understand.

67. Is there a need to consider additional safeguards for restrictions of liberty that fall short of DOL?

Yes, we feel that there are many situations that occur which fall short of a DOL but are still restrictions on a persons’ liberty which could be viewed as a restriction on their ability to exercise their human rights. For people living with dementia, all too commonly their human rights are not respected. Through our work in About Dementia, we have focused on human rights, helping those living with dementia and unpaid carers to understand and champion for their rights where they are so often overlooked in the belief of what someone else thinks is right.

“There is a hierarchy of human rights and dementia is on the bottom of the pile. I think it will remain there if we don’t stand up and do something.”

- Unpaid Carer speaking in 2022

Even if a situation falls short of a deprivation of liberty, any restrictions on someone’s liberty must be only used if deemed necessary, and even so, we strongly urge for additional safeguards to be in place. At the centre must be the person, their will, feelings and preferences in line with their fundamental human rights as outlined in the Charter of Rights for People with Dementia and their Carers in Scotland.¹³

Powers of attorney

68. Do you agree with the proposal to have prescribed wording to enable a power of attorney to grant advance consent to a DOL?

Yes, we agree with this proposal from the SMHLR. We are supportive of the power of attorney documents being as clear and specific as possible and believe that prescribed wording for granting advance consent to certain situations would be helpful to ensure the document is

¹³ Charter of Rights for People with Dementia and their Carers in Scotland.
https://www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf

legally secure. We would urge caution around this that there is no undue pressure of influence placed on individuals when making a power of attorney to add certain prescribed wordings without full understanding of what this means. Importantly, there must be earlier conversations between granters and attorneys around any prescribed wordings in the document so that the attorney fully understands what this means if and when the situation arises.

69. What are your views on the issues we consider need to be included in the advance consent?

We agree that if a power of attorney is to include advance consent to deprive the granter of their liberty, incapacity must be determined by an independent medical assessment. We agree with the proposal in the consultation for a granter to have to clearly set out in the power of attorney how they want their incapacity to be determined. If an independent medical assessment is used in the case where there is advance consent to a DOL, we urge that the wishes of the granter regarding how capacity should be determined, are still considered. We strongly agree that the changes should not affect the current provisions of section 16(6), stating that an attorney cannot place the granter in hospital for the treatment of mental disorder against their will.

The factors outlined in the consultation document, as proposed to be included in the wording of advance consent to a deprivation of liberty, we mostly agree with but have a few comments. In relation to the concept that the granter has ‘considered the circumstances in which it might be necessary to restrict their liberty or deprive them of their liberty ...’ we support this but ask that all the relevant information is provided in a clear and accessible way to individuals, to ensure they have all the information they need to understand what situations might occur. In relation to the proposal that the ‘terms of article 5 of the ECHR have been explained to the granter’, again, this must be done in a way that is person-centered and in a way that they will understand. It must be ensured that the individual is not simply given an overwhelming or complex pile of information about human rights conventions, which is seen as the completion of this task. There must be the opportunity for granters to ask questions and have the terms of article 5 explained to them in a way that they understand.

Finally, we agree with the proposal that if any adult, despite having granted advance consent for their attorney to deprive them of liberty, appears to later not want this, there must be a determination from the Sheriff. Whilst this might cause some delays to the process, if the human rights of the adult with incapacity are to be centre, and follow the principles of the AWI Act, then any suggestion that they have changed their mind, must be taken seriously.

70. What else could be done to improve the accessibility of appeals?

We believe that there should be the option to appeal a DOL from someone demonstrating an interest in the welfare of the adult. One of the key points we hear from people living with dementia and their unpaid carers surrounds the fear of making an appeal or complaint and the impact this could have on their care or support. To avoid this happening when someone has a concern for the welfare of a person placed under a DOL, there needs to be measures and reassurance in place to ensure that people know their appeal will be taken seriously, and that the care and support for the adult with incapacity is always prioritised during the appeal process.

71. What support should be given to the adult to raise an appeal?

To support an adult with concerns to raise an appeal, there must be accessible information and signposting to independent advocacy services which might be able to help them through the process. Legal appeals may seem intimidating to lay people and as such, knowing there is support from independent specialists could help to reassure people that this is a feasible option if they have concerns.

72. What other views do you have on rights of appeal?

No comment.

73. How can DOLs authorised by a power of attorney be appropriately reviewed?

We would suggest that the timeframe for review should be between 12-18 months to create parity with review of guardianship orders. There must be caution that if more regular reviews are held, reviews do not become less thorough and more of a 'tick-box' exercise.

Guardianships

74. Do you agree with the proposal to set out the position on DOL and guardianships in the AWI Act?

We support the inclusion of the functions and duties of a guardian within the AWI Act. If a guardianship is accepted as a lawful procedure under ECHR to deprive someone of their liberty, we support the inclusion of the position on DOL and guardianships within the Act to provide clarity and to ensure that the voice of the adult is centre of the process. However, we know that many guardians may not read the complex legislation in full. Therefore, we ask that the position is also clearly set out within supporting guidance and good practice documents which might be more accessible to those appointed as guardians.

75. In particular what are your views on the proposed timescales?

We tend to support the proposed timescales.

76. What are your views on the proposed right of appeal?

Similarly to our response to question 70 and 71, we are supportive of the proposed right of appeal.

77. What else could be done to improve the accessibility of appeals?

See response to question 70.

78. Do you agree with the proposal to have 6 monthly reviews of the placement carried out by local authorities?

Yes, we support this proposal, particularly that either the adult or anyone with an interest in their welfare would be able to request a review at any time. Echoing our response to question 70, it needs to be made clear to these individuals that more regular reviews are an option, and this must feel accessible and not intimidating.

79. Is there anything else that we should consider by way of review?

No comment.

Stand-alone right of appeal

80. Do you agree with our proposal for a stand-alone right of appeal against a deprivation of liberty?

Yes. We agree that if there is any concern for the person who is under a DOL, there should be the option to appeal against this. Fundamentally, the person must be at the centre of everything, and their human rights protected.

Role of the mental welfare commission (MWC)

81. Do you agree with our proposal to give the MWC a right to investigate DOL placements when concern is raised with them?

Yes, we agree with this proposal with the caveat that this must be underpinned with necessary resources and funding for any additional work this may create for the MWC.

Appointment of safeguarders/curators ad litem

82. Do you agree with the proposals to regulate the appointment, training and remuneration of safeguarders in AWI cases?

Yes, we agree with these proposals to ensure consistency and a better understanding of the role and responsibilities of safeguarders.

83. Do you agree with the proposals for training and reporting duties for curators?

Yes, we support these proposals.

84. What suggestions do you have for additional support for adults with incapacity in AWI cases to improve accessibility?

No comment.

Making financial abuse of an adult lacking capacity a criminal offence

85. Do you think there should be a specific criminal offence relating to financial abuse of an adult lacking capacity?

Yes, we strongly agree that financial abuse of an adult lacking capacity should be a specific criminal offence. Across our engagement with those with lived experience of dementia, there was a unanimous agreement that this should be the case with many people expressing their shock and lack of knowledge that this was not already the case as many assumed it was.

Whilst we believe that those who financially abuse an adult lacking capacity should face legal action, an interesting counterpoint was raised by some people we spoke to. There was an acknowledgement that for some attorneys, they are trying their best and it must be ensured that there is not over scrutiny or an increased feeling of a 'blame culture'. One person living with dementia suggested that the word 'deliberate' could be added in front of financial abuse. There should be clear examples of what constitutes financial abuse which recognises deliberate or calculated activities and activities which lead to it.

86. If so, should the liability be the same as for the welfare offence?

No comment.

Safeguards whilst awaiting discharge from hospital

87. Do you have experience of adults lacking in capacity being supported in hospital, despite being deemed to be no longer in need of hospital care and treatment? What issues have arisen with this?

As an organisation, the issue of adults with incapacity being delayed from being discharged from hospital, due to a lack of proxy being in place has been raised by our helpline, information and advice and dementia training teams. We know that this is a common experience for older people, with data showing that seven in ten patients facing delays to hospital discharge due to AWI legislation are forced to stay for over 6 weeks.¹⁴ This prolonged delay to leaving hospital for anyone, but especially those living with dementia, can be detrimental to their mental and physical health increasing the risk of distress, delirium and confusion.¹⁵ For example, for older people in hospital, 3 weeks in bed equates to 30 years of ageing in terms of muscle wastage.¹⁶

Delayed discharges also represent a significant and unnecessary cost to the public purse. The average daily bed cost of delayed discharges for NHS Scotland, based on the most recent available data (2019/20),¹⁷ was approximately £262 per bed per day.¹⁸ Looking at data for the 2023/24 financial year, where a total of 89,993 bed days were occupied by individuals aged over 75, who could not be discharged due to code 9 (AWI) reasons,¹⁹ this equates to an estimated cost of over £23.5 million for the year.

88. Do you foresee any difficulties or challenges with using care settings for those who have been determined to no longer need acute hospital care and treatment?

Based on the evidence mentioned in response to question 87, we are supportive of this issue being addressed. However, we foresee fundamental challenges with using other care settings. Most prominently, the care home capacity across Scotland is already at a breaking point with data showing there are 18% less care homes for adults in 2024 than there were in 2014.²⁰ The idea in principle of moving individuals to an environment that better suits their needs in principle is good, however, with care homes struggling with space, resources and staffing themselves, this would only increase pressure on their systems. Furthermore, for some individuals, especially for some people living with dementia, moving to a care home setting may not be any more beneficial if it is not what they wish for. There is the perception for some people living with dementia that once they enter the care home system in this way, they will not leave, whereas at

¹⁴ Health and Care Scotland Website (2021). *Adults with incapacity face longest discharge delays*.

<https://healthandcare.scot/default.asp?page=story&story=2861>

¹⁵ National Institute for Health and Care Excellence. *Hospital Care*. <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch3-hospital-care#:~:text=People%20with%20dementia%20often%20experience,return%20home%20to%20independent%20living.>

¹⁶ Scottish Government Health and Sport Committee (2019). *Looking ahead to the Scottish Government – Health Budget 2020-21: When is hospital bad for your health?* <https://bprcdn.parliament.scot/published/HS/2019/10/3/Looking-ahead-to-the-Scottish-Government---Health-Budget-2020-21--When-is-Hospital-bad-for-your-health-/HSS052019R10.pdf>

¹⁷ **Note:** Cost information is no longer submitted by NHS Boards to Public Health Scotland following the impact of the COVID-19 pandemic

¹⁸ Public Health Scotland (2021). *Delayed Discharges in NHS Scotland. Annual summary of occupied bed days and census figures: Data to March 2021*. <https://www.publichealthscotland.scot/media/10872/2021-11-16-delayeddischarges-annual-report.pdf>

¹⁹ Public Health Scotland (2024). *Delayed Discharges in NHS Scotland monthly. Figures for April 2024*. <https://publichealthscotland.scot/publications/delayed-discharges-in-nhsscotland-monthly/delayed-discharges-in-nhsscotland-monthly-figures-for-april-2024#section-3-1>

²⁰ Care Home Census for Adults in Scotland (2024). *Statistics for 2014 to 2024*. <https://publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2014-to-2024/>

least if they remain in a hospital setting until a guardianship order is approved, they may be more aware that they will be able to return home if this is what they wish.

Ultimately, we feel the best way to address the challenge of people being delayed from being discharged due to a lack of proxy in place, is to work to encourage everyone to have a power of attorney in place earlier, to prevent these situations arising as much as possible. Having the correct documents in place early and having open conversations with those appointed as proxies was one of the key recommendations provided by those we engaged with in response to our fictional storytelling scenario. We acknowledge that this doesn't necessarily help those already facing this issue, but believe that moving forward, prevention must be a key priority of the Scottish Government.

One of the key ways to encourage everyone to get a power of attorney registered early is to address the barrier of cost. We are aware that the costs solicitors charge to create a power of attorney varies significantly. For example, one carer during the engagement for this consultation spoke of their experience getting quotes from both her and her partners lawyers with a huge discrepancy in quotes between £50 and £550. One carer also mentioned how they had to pay for multiple copies of the PoA document with the official seal to be sent to different organisations including pension companies, hospitals and banks, which again adds up. Whilst legal aid is an option, this scheme itself has many issues which are beyond the scope of this response. To address this, we have several recommendations which we ask to be considered:

- As a minimum, there needs to be a further push on awareness of getting a PoA early and ensuring it is registered. This should have a particular focus on the potential issues which might arise if this is not in place.
- To address the barrier of costs of setting up a power of attorney we make two suggestions, either:
 - Create a standardised fee which solicitors can charge to help someone create a power of attorney document to ensure consistency for everyone.
 - Or ideally we ask that everyone receiving a dementia diagnosis (a group for whom a PoA is particularly important to have in place early), is offered a voucher following their diagnosis to create a PoA free of charge with a solicitor. Whilst an upfront cost, this would save public finances in the long-term by reducing delayed discharge costs.

89. What safeguards should we consider to ensure that the interests and rights of the patients are protected?

See answer to question 87.

90. What issues should we consider when contemplating moving patients from an NHS acute to a community-based care settings, such as a care home?

See answer to question 87.

Authority for Research

91. Should the AWI Act be amended to allow the creation of more than one ethics committee capable of reviewing research proposals involving adults lacking capacity in Scotland?

The topic of the governance of adults with incapacity to participate in research is complex, and not one which we believe comes with a straightforward answer but we tend to agree with this proposal. Not only will this help with any potential increase in proposals, but we also agree that having a system whereby researchers can appeal a decision with the option of a second committee reviewing the decision, could enable a fairer and more robust system of ethical review in Scotland.

92. In research studies for which consent is not required for adults with capacity to be included as participants, should adults with incapacity also be permitted to be included as participants without an appropriate person providing consent for them?

Informed by these thoughts of people with lived experience, we broadly support this proposal. We believe people with incapacity, including where this incapacity is deemed to be due to a form of dementia should be able to participate in research. As previously mentioned, to determine someone's will and preference to want to participate, previous participation could be considered. Additionally, we are supportive of the proposal outlining that this would mostly apply to studies which use patient data, rather than more invasive research, as those we discussed this topic agreed with.

As part of our engagement, the opportunity for individuals who lack capacity to be able to participate in research opportunities was discussed. Whilst opinions were mixed, some key points of consideration did emerge. Firstly, in one group, members felt that if the person who has subsequently lost capacity had been participating in research before their capacity declined, then this shows that this was a personal preference so if they demonstrate a wish to continue participating in similar research even if their capacity might have declined, this should be allowed. Several people also noted that they felt it should depend on the nature of the research, for example, it would be ok for less invasive research but not for the more intensive clinical style studies.

Interestingly, amongst one of the groups we engaged with, the perception of research appeared to be quite negative. There were comments relating to the need for research to be actionable and for researchers to be explicitly clear what will be done with the research, especially if people with a dementia diagnosis were participating.

A question was raised by one couple as to whether those with a dementia diagnosis would be able to participate, even if this legislation changed, as there remains a stigma that a dementia diagnosis immediately equates to someone being incapable of participating in research. They shared their personal experience of being turned away from accessing research opportunities due to a diagnosis. Both groups appeared to have the conclusion that if someone with a dementia diagnosis wished to participate in research, they should be supported to do so, if the support is in place to help them make this decision.

93. Should Scotland A REC (or any other ethics committee constituted under Regulations made by the Scottish Ministers in the future) have the ability to determine that consent would not be required for adults with incapacity to be included as research participants, when reviewing studies for which consent would also not be required to include adults with capacity as research participants?

See above response to question 92.

94. Should the AWI Act be amended to allow researchers to consult with a registered medical practitioner not associated with the study and, where both agree, to authorise the participation of adults with incapacity in research studies in emergency situations where an urgent decision is required and researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative in time?

No comment.

95. Should the AWI Act be amended to allow researchers to enroll adults with incapacity in research studies without the consent of an appropriate representative of the adult, in emergency situations where a decision to participate in research must be made as a matter of urgency, where researchers cannot reasonably obtain consent from an appropriate representative of the adult, and where researchers act in accordance with procedures that have been approved by Scotland A REC (or any other ethics committee constituted by regulations made by the Scottish Ministers)?

No comment.

96. Should the AWI Act be amended to permit researchers to nominate a professional consultee to provide consent for adults with incapacity to participate in research, in instances where researchers cannot reasonably obtain consent from a guardian, welfare attorney or nearest relative?

No comment.

97. In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the AWI Act be amended to allow adults lacking capacity to participate in research that investigates conditions that may arise as a consequence of their incapacity?

We are generally supportive of this proposal. Reiterating the other points we have made, if an adult who is seen as lacking capacity is supported to express a preference to participate in research, regardless of if this is in relation to the condition which is deemed to cause their incapacity, they should be supported to do so. Especially where someone may lack capacity due to a dementia diagnosis which is commonly in those in older age, it is highly likely they may be living with other long-term conditions associated with the ageing process, including diabetes, cardiovascular disease, hypertension and musculoskeletal disorders.²¹ Therefore, the impact of their other diagnosis should not prevent them from participating in other research which could help build further understanding of the impact of co-morbid conditions.

Overall, we believe that what is required is a rethink of how a dementia diagnosis is viewed in the research world. Just because someone has received a diagnosis, it doesn't mean they should be excluded from all research, whether relevant to their dementia diagnosis or not. This links

²¹ National Institute for Health and Care Excellence (2018). *Dementia: Assessment, management and support for people living with dementia and their carers. Chapter 18 'Assessing and managing comorbidities.*
https://www.ncbi.nlm.nih.gov/books/NBK513207/pdf/Bookshelf_NBK513207.pdf

into the wider campaign of awareness that a dementia diagnosis does not mark the end of new opportunities and if supported correctly to be able to exercise their legal capacity, people living with dementia can participate in a range of activities, including certain research opportunities, which can potentially help them in turn feel more fulfilled and empowered.

98. In addition to being permitted to participate in research that investigates the cause, diagnosis, treatment or care of their incapacity, should the AWI Act be amended to allow adults lacking capacity to partake in research that investigates conditions they experience that do not relate to their incapacity?

Yes, we tend to agree with this proposal. See response to question 97 above.

99. Should the AWI Act be amended to allow adults with incapacity the opportunity to participate in any research; regardless of whether the research explores conditions that relate to their incapacity or investigates conditions that they experience themselves?

Yes, we tend to agree with this proposal. See response to question 97 above.

Want to find out more?

As Scotland's national charity supporting people over the age of 50, Age Scotland works to improve older people's lives and promote their rights and interests. We aim to help people love later life, whatever their circumstances. We want Scotland to be the best place in the world to grow older.

Our Policy, Communications and Campaigns team research, analyse and comment on a wide range of public policy issues affecting older people in Scotland. Our work is guided by the views and needs of older people themselves.

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