

# Alzheimer Scotland

## Scottish Government – Adults With Incapacity Reform

### 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](http://www.alzscot.org)) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to respond to this consultation and acknowledges the experiences and knowledge shared by people with dementia, carers, colleagues and professionals which has informed our response.

Alzheimer Scotland's response is grouped into headings which reflect the main proposals within the consultation document. Some of our response reiterates points made in our response to the Scottish Government's previous consultation on the Scottish Law Commission's (SLC) proposals; many of the issues raised within that response remain and have not been addressed in this consultation.

### General Comments

#### Reform of Current Act

Alzheimer Scotland is aware of the inherent problems with the Adults with Incapacity (Scotland) Act 2000 and welcomes the Scottish Government's review of the legislation. However, we believe that a number of the issues with the current approach are to do with the implementation of the 2000 Act in practice; therefore, some of the proposals are likely to experience the same issues.

We therefore believe that the 2000 Act does not require extensive reform, rather, more consideration should be given to its implementation and how compliance can be ensured.

#### Approach of Act

People with dementia, carers and professionals have shared that a key issue with the 2000 Act is the 'front-loaded' nature of the legislation; there is considerably more focus on what happens at the beginning of the process (e.g. through planning a POA, registering with the Office of the Public Guardian etc.) rather than ensuring a consistency and adherence throughout the duration of the process. For example, POAs and Guardians must articulate the powers they are seeking in advance as part of the respective processes. For complex, progressive conditions such as dementia, attempting to predict what may be needed in future is incredibly difficult and potentially harmful if carers are expected to apply for new

powers each time they require further powers or unanticipated circumstances occur outside the scope of what has previously been granted – especially where the person may be in a crisis situation.

Alzheimer Scotland understands the rationale for approach of the 2000 Act, however, we believe that a balance must be found between the need for due process and legal compliance, with the need to improve the experience of people who use the system. There is concern amongst people we consulted that the new proposals for POA and Guardianship further entrench this approach, requiring more specific and detailed information for future powers, particularly in relation to Significant Restrictions of Liberty (SRoL).

As such, we recommend that this should be given further examination as part of the reform of the Act.

### Human Rights Based Approach

Alzheimer Scotland welcomes that the proposals draw on drivers such as the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) and domestic law to ensure compliance. As part of this, it is welcome that there is acknowledgement of the need to move towards supported decision making as an integral part of reforming the Act.

However, we remain uncertain that the proposals set out within the document are fully compliant and in some cases, we believe that the new processes do not embody the ethos of a human rights-based approach.

As a broader issue, it is imperative that the system prioritises using the skills and abilities of the individual, involving them in decisions as far as possible, and including proxies as a key part of practice. Both people with dementia and their carers have emphasised to us the strain that the process of a person losing capacity can have, as well as the pressure and emotional nature of making decisions on behalf of a person. People with dementia have shared that they worry about the pressure and stress placed on their spouse/relative, noting that they were first and foremost a family member, a carer second. They have further told us that if they felt making proxy arrangements would impact negatively on their spouse or relative, they would be less inclined to do so. Similarly, carers have shared their personal experiences, with some reflecting on the difficulty of being included and involved in decision-making about a loved one's health and social care arrangements, even where they hold relevant proxy powers.

This demonstrates that a fundamental challenge lies in implementation of the Act, not with the Act itself. Alzheimer Scotland therefore believes that it is imperative that the legislative framework and health and social care professionals accommodate the needs of the person with dementia and provide a strong basis of support to proxy decision makers.

### Definition of Incapacity

Alzheimer Scotland does not believe that the definition of capacity should be omitted from the reform consultation subject to the review of the definition of ‘mental disorder’ under the 2003 Act. Establishing capacity/incapacity is central to many of the underlying challenges in the implementation of the legislation, including recognising the distinction between legal capacity and decision-making capacity. We believe that subject to the findings of the review, this must be subject to further scrutiny and engagement with stakeholders as the process of reforming the 2000 Act continues.

### **Significant Restriction of Liberty Definition (SRoL)**

#### Definition of SRoL

Alzheimer Scotland broadly welcomes proposals around ‘Significant Restriction of Liberty’ (SRoL), recognising the development of the proposals by the SLC, incorporating recent developments in jurisprudence. Additionally, we welcome the definition set out on p.12, believing it to be well developed and defined for identifying a person with incapacity whose liberty may be restricted. Additionally, we are pleased that there has been additional context placed around the new definition, recognising that SRoL should be based on the circumstances of a person and potentially occurring in a variety of settings, not solely in institutional care settings.

Alzheimer Scotland does not understand the rationale for removing ‘*The adult is unable by reason of physical impairment to leave the premises*’ which had previously been included in the SLC’s definition. Indeed, in our prior response, Alzheimer Scotland proposed that this aspect of the definition should be expanded to include to include visual impairment, as well as physical impairment. Deterioration in eyesight because of neurological changes, as well as conditions such as cataracts, may reduce a person’s ability to navigate their way out of a building or ward.

As we have noted previously, good design for people with dementia incorporates distinctive colours for doors and clear signage in order to ensure that people with dementia can navigate their environment. As such, it could be considered that environments which fail to incorporate these design elements, even if unintentional, are restrictive to the liberty of people with dementia and/or visual impairments.

Alzheimer Scotland therefore encourages the Scottish Government to restore the physical mobility component of SRoL, expanded to include visual impairment.

#### Technology and SoRL

Alzheimer Scotland is disappointed that the consultation document does not reference the use of technology other than two brief references in the context of video-links in Sheriff Courts and in the Mental Health Tribunals for Scotland (MHTS).

Alzheimer Scotland addressed this point in the SLC consultation and we remain of the view that the use of technology and its potential impact on the rights of an individual are potentially incompatible with existing legislation.

The SLC's original report from 2014 addresses this point directly:

*3.21 ... We have ascertained that measures are also being adopted to prevent patients, usually those who have dementia, from leaving hospital wards. These measures can include electronic tagging or close monitoring of ward exits to prevent departure. Notwithstanding the benevolent motivation underlying such measures, the consequences of confining a patient to a hospital ward by use of such measures appears to us to be de facto detention, therefore incapable of authorisation under section 47, and to require an authorisation process.*

*4.15 It is concerning that individuals are remaining in hospital when their medical condition does not require them to be there. It is particularly concerning if the reason for this is connected to legal process ... If measures to keep them there, such as electronic tagging, are being used, there may even be a breach of Article 5.*

Whilst these refer specifically to hospital settings, the implications for other care settings are likely to be similar in nature.

Alzheimer Scotland is aware through its own work and through engagement with stakeholders that there is an increasing use of technologies to support people with dementia in both community and acute settings; in some circumstances, this will be the 'least restrictive' option, in keeping with the principles of the 2000 Act.

However, we also understand that this technology has also been used in the past in acute settings for people who have impaired decision-making capacity and were prone to leaving wards or hospital buildings. If this technology is being used as a de facto restraint to monitor and restrict a person's movements, resulting in them being confined within a hospital environment or community setting (including the person's own home), then there is merit in expanding the definition of SRoL to encompass the use of technology for this purpose.

The Mental Welfare Commission's 'Decisions about technology' guidance, published in 2015, states that:

*If the technology is preventing someone from leaving the place where they are being cared for, this is an important factor in deciding whether or not there has been a deprivation of liberty.*

Despite this, Alzheimer Scotland does not believe that the proposed definition of SROL adequately addresses the use of such technologies in this manner; if technology is to be used in this way, it must have a legal basis.

Alzheimer Scotland therefore believes that the omission of reference to technology, particularly within the definition of a SRoL, represents a real risk of technology impinging on the liberty of an individual, with no statutory safeguards in place. Therefore, Alzheimer Scotland again proposes that the definition of SRoL be amended to include technology.

### **Supported Decision-Making (SDM) Principle**

Alzheimer Scotland understands the rationale behind the proposed introduction of an additional principle on supported-decision making (SDM). We fully support the intention behind this, however, believe that the new principle for SDM, as drafted, does not meaningfully enhance the Act, duplicating principles three ('take account of the wishes of the person') and five ('encourage the person to use existing skills and develop new skills').

Whilst Alzheimer Scotland is not opposed to the creation of a new principle per se, we believe that the resolution of the issues is as much an issue of practice and implementation of the current principles and code of practice. We are therefore not convinced that the creation of a new principle will achieve the intended outcome.

As such, Alzheimer Scotland believe that slight amendments could be made to principles three and five to explicitly reference SDM, setting it out as one of the fundamental ways in which effect may be given to the principles. As part of this, amendments could be made to the code of practice to provide more detail on how the approach should be used, with additional resources and materials made available to health and social care organisations and professionals.

Drawing on the experiences shared by people with dementia and carers, we are not aware of SDM being applied widely across different health and social care settings. Alzheimer Scotland appreciates that there will be a number of reasons for this, including a lack of familiarity with the concept, as well as challenges where the person has profound difficulties in communicating as a result of cognitive impairment and/or diminished decision-making capacity. We therefore, welcome that the Scottish Government is currently undertaking work explore the development of a framework for SDM, particularly around how this may be embedded in the practice of health and social care professionals working with people with some level of decision-making capacity.

### **Power of Attorney (POA) Documents**

Alzheimer Scotland cautiously welcomes the proposed changes to Power of Attorney (POA) documents as we believe that the existing provisions around the documents are insufficient and can be problematic both for the cared for person and the proxy.

#### Activation

In principle, the introduction of requirement for the POA to articulate how incapacity should be determined before the powers come into effect is sound; however, we believe that the implementation of such a provision would be potentially problematic. For people with

progressive conditions such as dementia, capacity is not binary and it would be incredibly difficult to predict the point (or points) at which the POA (or parts of it) should be activated, as well as identifying when this had been reached.

Whilst we are aware that some POAs currently make provision for who determines the capacity of the person, it is difficult to envisage the documents accommodating instructions as to how capacity is to be determined especially in relation to different powers at different levels of decision-making capacity.

Alzheimer Scotland also seeks clarification on whether the omission of this would result in the POA document becoming invalid. If this is the case, Alzheimer Scotland is concerned that many existing POAs would cease to be valid, potentially resulting in people being required to apply for a guardianship order.

#### Assessing Capacity – Expansion of the Section 22 List

Alzheimer Scotland is aware of existing concerns around the assessment of capacity between different professionals. Whilst there is not a single test or way of identifying capacity, we believe that in the interests of consistency and due process, if the Scottish Government is minded to expand this list, it must be done in such a way as to ensure that there is greater consistency in the way in which the incapacity of individuals is determined across clinical and non-clinical professions. Furthermore, it must be done in such a way as to address the difficulties which arise in assessing capacity, from variations in who sees the person, the time(s) at which they see them and what criteria they use to assess the person.

The professional who assesses capacity be skilled and trained in the complexities of assessment in dementia. It cannot be done on the basis of a simple cognitive test but requires history taking from the person and the person's family/carers, with practical testing relevant to the type of capacity being tested. This may also require sensitive assessment of changes judgement and related issues.

#### Deprivation of Liberty Authorisation

Alzheimer Scotland is also pleased that the consultation acknowledges that issues around potential Deprivations of Liberty and the authority of POA to make arrangements for the incapacitated person, particularly where they may not wish to be subject to said restrictions. From the experiences of the people we support, care transitions (often from acute hospital settings to care homes) have proved problematic, with many POAs believing they had powers to move a person, only to be advised that they required Guardianship to authorise the transition.

The proposals within the consultation are a positive development, however, we are concerned about the potential future implications of such a prescriptive approach (advance consent conditions) to the wording required within the POA document. As has been demonstrated in the past, an inflexible approach in the wording or interpretation of the 2000 Act can lead to much uncertainty and difficulty about the validity of the POA document and the provisions within it.

Whilst, the rationale to avoid ambiguity through clearer wording is understandable, we have concerns about the consequences of this approach:

- If the wording is incorrect for the DoL/SRoL, is it only the specific provision which is invalid or the entirety of the document?
- This does not address the problem of existing POAs which will continue to be insufficient under the proposed changes.
- Proxy-decision makers may still find themselves unable to make decisions in crisis-points which may be beyond the scope of the POA.

Alzheimer Scotland believes that provision is another aspect of ‘front-loading’ within the legislation, which tries to make provision for a broad-range of circumstances, whilst remaining legally compliant. However, we believe that in this provision there must be a greater focus on how people may be affected in practice.

Such decisions may be taken at particularly difficult times for both the proxy and the cared for person, potentially when at a crisis point. In such circumstances, where a POA is in place and allows the person make placements, requiring a person to go through an additional process in the form of Guardianship has the potential to generate additional stress, costs and delay. Alzheimer Scotland understands the desire to ensure that there is greater proportionality for the powers of proxy decision-makers and the desire to establish a robust and consistent approach to authorising SRoL. However, whilst we agree with this aim, we remain concerned that this leaves considerable numbers of people facing circumstances whereby they must go through a Guardianship order, even where a POA is in place. We do not believe that it is appropriate or should be necessary that in such circumstances, a mechanism such as the proposed short-term placement orders should be used.

Alzheimer Scotland therefore believes that the 2000 Act should be amended to include another mechanism allowing POAs to place people in situations which may meet the definition of a SRoL. Additional safeguards could be built in through requiring the decision to be discussed through relevant professionals, e.g. care manager, specified clinical professionals etc. As part of this, a more robust system of review would be useful to ensure that registered POAs containing SRoL powers do not continue indefinitely without review.

In both instances, Alzheimer Scotland is concerned about the implications for existing POAs which have been made prior to the changes. We would welcome further information on whether these POAs would be ‘grandfathered’ to avoid current POAs becoming invalid as a result of the proposed changes to the 2000 Act.

### **Official Supporter**

Alzheimer Scotland believes that there is merit in the establishment of an Official Supporter, recognised in law, as a way of embedding Supported-Decision Making (SDM). In particular, people with dementia and their carers were enthusiastic about the scheme as they were keen for a wider recognition that for people with dementia, capacity is not binary and that

with support from a carer/loved one/friend etc., people could be supported to make decisions about their own affairs.

However, some issues have been identified about this approach which Alzheimer Scotland would like further detail on before offering support for the scheme.

The first relates to the implementation of such a scheme. If the Scottish Government is minded to adopt the scheme as it exists in Australia or Canada, this has the potential to create additional complexity within an already complex system, including another title within mental health legislation (POA, Guardian, Named Person, Listed Initiator etc.). In addition, the necessity of registering creates an additional bureaucratic element. This has the potential to be confusing for the cared-for person, the supporter and professionals, if there is not widespread understanding of each role and what each can or cannot do.

The second query relates to the necessity of creating statute for this proposal. If the supported-person is in a position to make a decision about who they wish to be their Official Supporter, they are likely to be able to articulate their wishes about a family member or other person being kept informed about matters which are relevant to them. The consultation document provides little by the way of detail as to what the legal status of the Official Supporter would be and how this would be fundamentally different from a person without this recognition who currently supports the person.

If the Scottish Government is proposing that establishing an Official Supporter is the only way in which the intended outcomes may be achieved (by providing a legal basis which satisfies data protection legislation around the sharing of personal and sensitive information), then Alzheimer Scotland supports its establishment in law. However, if the same outcomes can be achieved without statute, this would be preferable.

## **Graded Guardianship/Corporate Guardianship**

In the course of its consultation with its networks, Alzheimer Scotland received a broad range of comments in relation to the Graded Guardianship proposals.

### Supporting Arguments for Graded Guardianship

Carers in particular were supportive of the proposals, with some expressing frustration with the current process of applying for Guardianship which is felt to be complex, costly and burdensome. In instances where the cared-for person cannot be moved from an inappropriate setting (e.g. in an acute setting where there is no clinical need to be there) because of SRoL considerations, the time delay of the current system was also identified as an issue. It was felt that if the system could be streamlined and responded quicker, this would likely improve the quality of life for the person, reduce stress and burden on the carer and reduce the length of time people remained in inappropriate care settings.

It was also felt that given the proposed tiered structure and the ineffectiveness of different elements of the current structure, abolition of Access to Funds and Intervention Orders, were felt to make sense.

There was also strong support for the proposed tiered structure, although there were questions as to the distinction between tiers one and two; whilst acknowledging the need to have a more stringent process for potential SRoL cases, it was felt that other distinctions on the basis of assets would be arbitrary. Additionally, the flexibility of the system to allow for the referral of cases up or down tiers depending on the nature of the Guardian application was welcomed.

Furthermore, there was support for the time limits on powers, with the three year limit (plus five years after renewal) seen as a reasonable time. However, carers also felt that for progressive conditions such as dementia, where there was little prospect of a significant improvement in a person's decision-making capacity, there should be a 'fast track' renewal to review if the powers remained appropriate or if amendments should be made.

### Concerns About Graded Guardianship

Whilst Alzheimer Scotland welcomes the intention to improve people's experience of the process of applying for Guardianship, both in terms of the timescales involved and the experience of the process, we believe that there are inherent problems in the proposed approach, particularly at Stage One.

Alzheimer Scotland's primary concern is with the lack of oversight, checks or balances for the proposed stage one application; this provides a considerable level of powers and decision-making ability, without stringent checks on the person applying for Guardianship. Administrative and procedural convenience must not undermine mechanisms which help to ensure that safety of people whose incapacity leaves them at risk of harm. Both carers and professionals expressed the view that the proposed application at stage one is insufficiently robust and does not contain sufficient safeguards in place to identify people that may be unsuitable for guardianship. Whilst we welcome the intention to simplify the process and improve the experience of those applying for Guardianship, the scheme must be sufficiently stringent to ensure that people who would seek to harm or exploit vulnerable individuals are prevented from doing so. It is not apparent that the Stage One process is sufficiently robust to achieve this.

Both carers of people with dementia and professionals expressed the view that based on the proposed changes to the Graded Guardianship, it is not immediately apparent why people would take out a POA, when the Guardian Process at Stage One would potentially be a more straightforward and cheaper process. Whilst Alzheimer Scotland would actively encourage people to continue to take out POAs, the Scottish Government must address the potential implications that have arisen as a result of these proposals.

A fundamental issue with the proposed approach lies in the continued 'front-loading' of the application process, especially through the proposed 'checklist' of powers. Whilst we

welcome that the move towards ending indefinite Guardianships and those which grant broad powers irrespective of appropriateness, we have concerns the impact of a shift towards only granting powers required at the point of application. This presents difficulty for fluctuating and progressive conditions such as dementia; where people's cognitive function is likely to deteriorate further, additional powers may become necessary at short notice and in crisis situations. In such circumstances, requiring further application or procedure has the potential to cause harm for both the proxy and the person.

Alzheimer Scotland believes there is merit in the tiered approach proposed by the Scottish Government, however, we believe that the multiple processes in place for applications at different stages represents an added complexity to the current system. We suggest that the application process could be made more straightforward by a simple extension of the proposed form for Stage One, which could be sectioned depending on the level of powers being sought, with clear indicators about certain powers or circumstances requiring a further different 'stage' of application (e.g. a prompt advising that SRoL powers or exceeding a set capital value require a Stage Two application).

Additionally, we believe the proposals are unduly burdensome on carers, particularly in relation to the need to consult with relevant persons. As the OPG will receive the paperwork and be informed about who the relevant persons are, we believe that the OPG could absorb some of this process to remove some of the bureaucratic burden on the applicant.

#### Organisational Guardianship/Management of Resident Finances

Alzheimer Scotland does not oppose the idea of providers taking on the role of Guardianship in a corporate capacity, however, we believe that there are significant risks attached to this proposal. At this stage, we do not support the merger of Management of Residents Funds into Graded Guardianship. Without further information as to how this would operate in practice, it is difficult to comment further.

We are concerned that a provider acting under these provisions is inevitably conflicted between their professional obligations and the interest of the person. Alzheimer Scotland believes that at present, the external regulation and monitoring of services provides a good level of oversight of how this works in practice, within the context of limited powers.

Whilst there may be merit in expanding the powers on this list and to support organisations to support an individual, the current low uptake on the part of organisations should not mean that administrative convenience becomes the primary driver of reform. As the proposals would significantly expand the powers of providers over the lives of the individual, including broad powers over their finances, a correlated increase in checks and balances is necessary. Without these, the proposals leave vulnerable people at considerable risk, with insufficient oversight or monitoring.

## Support and Supervision of Guardians/POAs

Alzheimer Scotland welcomes the document addressing issues around support and supervision for Guardians. Many carers we spoke with, who had taken on proxy decision making roles, shared that they felt inadequately advised or prepared about the responsibility that comes with the role or how it works in practice. Particularly for conditions such as dementia where decision-making capacity may fluctuate, carers shared that they often find it difficult to support a person, particularly where the person may not have insight to or does not acknowledge their condition. Additionally, we are aware of cases whereby carers have been encouraged to seek proxy-decision making powers by creating a POA, without the effects of this in relation to other supports, such as SDS, having been explained to them.

Whilst this does not require a change in the primary legislation, a change in the Code of Practice, in addition to an increase in the provision of information, resources or materials available for people considering applying for a Power of Attorney or Guardianship order. As part of this, changes should be made to the Code of Practice, as well as a coordinated approach across different professions and sectors to ensure that those considering taking on a proxy decision making role understand fully understand the legal obligations of the role, as well as other implications. As part of this, there is potentially a role for solicitors drafting a POA and Sheriffs or the MHTS (for Guardianship) to ensure that people understand what is expected of them before granting the proxy.

### Advocacy

Alzheimer Scotland believes that there should be a requirement for advocacy support to be available for people with dementia and/or their families and carers, particularly where proxies may be exercising powers, applying for powers under the Act or where they are engaging with professionals who are acting under the AWIA. We believe that there is an inconsistency that the Mental Health (Care and Treatment) (Scotland) 2003 makes provisions for individuals to be offered advocacy. The experience of acquiring and exercising proxy powers is often a profoundly difficult and emotional experience both for the person with dementia and carers. It is therefore essential that people have the opportunity to speak to a skilled advocacy worker who can help them understand the statutory basis of the action taken, ensure that their views are heard as part of the process and can, if necessary, work with them through appeals.

### Supervision

Whilst we believe that the proposals around Graded Guardianship have addressed the concerns about the lack of review of powers, concern remains amongst the people with whom we have engaged about the lack of safeguarding around POAs and the comparatively light touch nature of the Act.

Alzheimer Scotland believes that whilst the system should not be unduly burdensome and deter people from seeking a POA, there is a need to ensure that due process is observed

and safeguards are in place to protect vulnerable persons. We continue to be of the view that administrative convenience should not take precedence over the safety of the person who is subject to proxy decision making. As articulated previously, Alzheimer Scotland does not believe that the proposals sufficiently address the need for improved safeguarding, particularly in relation to the open-ended nature of provision under POAs.

In addition, we are broadly supportive of the proposed register of high-risk Guardianship orders, to provide shared information between the OPG, MWC and LA social work services. However, this will require clear and agreed processes for identifying issues relating to identifying potential risks and harms, reporting and response. This will also require linking across to the Adult Support and Protection (Scotland) 2007. Alzheimer Scotland is aware that at present there are challenges about the process for raising concerns in relation to about adults with incapacity, particularly where concerns raised locally with national bodies are frequently are treated as issues to be resolved under the 2007 Act, placing the responsibility on LAs.

## **MHTS/Sheriff Court**

### Support for Moving the Forum to MHTS

Alzheimer Scotland welcomes the proposals to shift the primary forum of decisions on Guardianships to the Mental Health Tribunal for Scotland (MHTS). It was felt that the current system through Sheriff Courts was potentially stigmatising to people with dementia and carers (by virtue of the setting) and more adversarial in nature. Furthermore, professionals with experience of the system highlighted significant variation in the interpretation of the 2000 Act between Sheriffs and Sheriff Courts; one of the reasons attributed to this was the different numbers of cases dealt with by Sheriffs, which often differed significantly between rural and urban areas (though concern was expressed about losing the knowledge of Sheriffs with considerable experience in this area). It was hoped that such variation would be reduced by a more consistent approach through the MHTS – though it was noted that this would require ensuring that MHTS members were supported through training to ensure consistency of decision making and approach between legal, clinical and lay professions on the panel.

Alzheimer Scotland also heard professionals express the view that by moving the forum to the MHTS, it may move Scotland closer to a more coherent approach to its mental health legislation, bridging the gap between the 2000 Act and 2003 Act. It was felt that the internal appraisal system of the MHTS was a strength of the system and would further help reduce inconsistency in the decision-making process for Guardianships.

### Concerns in Relation to Moving the Forum to MHTS

It is our understanding that people with dementia often do not participate in MHTS proceedings under the 2003 Act. Whilst in some cases there will be legitimate reasons which prevent the person from taking part, if the MHTS does not offer a more inclusive and accessible process or forum (than Sheriff Courts), it may be considered that it does not

represent a significant improvement on the current system. We therefore consider that there must be significant investment of time and resource to ensure that the process gives the person every opportunity to be involved; we believe that this must be underpinned by both access to formal advocacy and the embedding of support decision making.

Furthermore, it is evident that this potential change will require a significant allocation of resources to ensure that the MHTS, regardless of the system of Guardianship in place, must be sufficiently and sustainably resourced, to ensure that members have the knowledge to effectively apply the Act and its principles, to be able to deal timeously with the number of applications and to ensure people are supported to be meaningfully involved in the process as far as possible.

## **Detention for Physical Treatment, Short Term Placement Orders**

### Extension of Section 47 Certificates

Alzheimer Scotland broadly agrees with this proposal and recognises that a number of the previous issues when the proposals were initially made in the SLC report have been addressed. We understand the rationale set out in the consultation document allowing medical professionals to make the decision to detain a person in the context of the acute environment, i.e. to detain the person for the purpose of treatment which may necessitate timeous action. However, we do not believe that referencing the Principles of the Act will in itself ensure that carers and proxies are included in the decision-making process.

In relation to removal to hospital decisions, we would welcome closer alignment to the 2003 Act, where detentions can be authorised in emergency situations. For removal to hospital, Alzheimer Scotland would support provision of this power, so long as it was clear that every attempt had been made to resolve this by other means and that the carer and/or proxy had been consulted, unless there were mitigating circumstances which necessitated the immediate removal to hospital. In these situations, discussions with the carer and/or proxy should take place as soon as possible thereafter

Alzheimer Scotland would welcome further detail on how the appeal process would work and where the appeal should be made. In our response to the previous SLC proposals, we expressed concern that a person with incapacity could be subject to a SRO for an indeterminate period before the family or carer are informed and have the opportunity to appeal the decision.

It is important to recognise that not everyone with incapacity will have a family member or someone who can challenge detention, where the person does not have a family member, no local authority guardianship order in place or where a person has had no prior contact with statutory services. Given that there is no provision for MHO involvement in this process, we believe this underscores the need for access to advocacy support and merits further consideration of how safeguards can be put in place for these individuals.

A previous concern from the SLC proposals concerned the absence of a central oversight or recording arrangements for certification for a SRoL/detention in a hospital setting. The 2003 Act requires hospitals to inform the Mental Welfare Commission of detention, with deprivation and other aspects of treatment only authorised for three days without involvement of a Mental Health Officer (MHO), with detention over a month requiring a tribunal to make a decision. We are aware that external monitoring takes place through external bodies, including the Mental Welfare Commission and Healthcare Improvement Scotland, however, there is a similar lack of information on how effective and appropriately these provisions are used across Scotland.

Whilst Alzheimer Scotland does not suggest that there should be an identical process in place, the proposal as set out creates further inconsistency across the 2000 and 2003 Acts. Given the longer period of detention, lower threshold of authorisation (single medical practitioner with no MHO involvement) and no external monitoring, we suggest that the proposals do not provide sufficient checks and balances to protect the individual.

### Short Term Placement Orders

Alzheimer Scotland does not support the creation of Short Terms Placement Orders, as we are not persuaded of the necessity of such a provision. Without further details on the process of appeals, how the person and/or proxies would be involved and the application of this in practice, we remain unconvinced that this is a positive development which is in the best interest of persons with incapacity.

Particularly in relation to people with dementia, we are concerned that the ability to move a person on a short-term basis has the potential to cause significant harm the person if they are temporarily placed in an unfamiliar setting, then moved again soon after. This has the potential to cause the person to become distressed and disorientated, potentially leading to an increase the progression of the person's cognitive ability. This has the potential to result in a short-term placement becoming a longer-term placement, even if this is not in the interests of the person or in line with their wishes.

Alzheimer Scotland is also concerned about the potential for these orders to be used in instances where it is in the organisational interest for the person to be moved, not necessarily in the interests of the person. As the orders are discussed in the relation to the section 47 certificates, we are concerned that these orders may be used in relation to ensuring people are discharged from acute settings as quickly as possible, where long-term community-based services or supports may not immediately be available.

### **Advance Directives**

Alzheimer Scotland broadly supports removing the current ambiguity which currently exists around Advance Directives through giving legal effect to these documents. However, as with existing POAs and Guardianship orders, the effectiveness of this proposals is contingent on good implementation, as well as good awareness and understanding both by professionals and applicants. Too often, carers (as proxies) are not consulted or involved in decision

making regarding the person with incapacity; unless such issues around awareness and implementation are addressed, there is no reason to believe that Advanced Directives would not face the same difficulties.

Additionally, it is important to consider that in relation to an individual's care, particularly for adults with incapacity, there is we need to consider the cluttered landscape of anticipatory care planning, living wills, Advance Directives, advanced statements etc. This is the source of much confusion for people planning for their future care and for proxies trying to ensure that the individual's wishes are respected.

Alzheimer Scotland would welcome further detail on how Advance Directives would operate in practice and their legal position, in relation to other legal entities. Where a person does not have capacity (as determined by a clinician) but can articulate a preference, has a POA/Guardianship, plus an advanced directive (which the person may or may not still agree with), it is not clear which takes precedence, where there is conflict between one or more aspects. For example, could an attorney disregard an Advance Directive, if it was argued the circumstances go beyond what the person envisaged when writing the directive years previously? Additionally, clarification on point at which an Advance Directive comes into effect would be helpful.

Whilst Alzheimer Scotland understands the rationale for creating this provision, we are concerned that the creation of another document potentially creates confusion, especially as the name is similar to Advance Statements under the 2003 Act. Whilst we understand that the purpose of both is different and that not every person subject to one Act will necessarily be subject to the other, there is some overlap in terms of setting out preferences for future care. In the interests of creating closer alignment between the 2000 and 2003 Acts, we believe there is merit in examining the possibility of creating a single document which applies across both Acts; this may potentially encourage take up if it was understood that its legal standing would apply across broader range of settings and circumstances.

## **Participation in Research**

Alzheimer Scotland is concerned by the proposals in relation to research and the inclusion of people who do not have capacity to consent. We are particularly concerned in relation to the question of whether clinicians should be able to authorise a person with incapacity (where there is no guardian or relative). This proposal goes against the tenets of biomedical ethics, does not align with a rights-based approach and cannot be justified given the vague nature of 'potential benefit'.

The only possible exception to this should be in situations where there is explicit instruction or views expressed in relation to participating in research, for example through an Advance Directive. However, given that the principle of autonomy requires ongoing and informed consent, it is difficult to envisage a sufficiently detailed or comprehensive Advance Statement that would satisfy participation.

Additionally, there is insufficient detail within the consultation as to what constitutes 'emergency research'. As such, Alzheimer Scotland is not persuaded that there is justification for a significant legislative change to authorise the inclusion of people with capacity to be entered into emergency research.

However, Alzheimer Scotland does support the proposed changes with regards to clinical trials of non-medicinal products being approached in the same way as clinical trials of medicinal products, using the existing legislative framework for involving adults with incapacity in research.

## **Conclusion**

Alzheimer Scotland believes that the consultation document has highlighted a number of important issues with the Adults with Incapacity (Scotland) Act 2000 in its current form. It is demonstrable that the legislation requires reform, however, we feel that many of the issues would more effectively be remedied through a greater focus on implementation and practice, not significant reform of the Act.

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