NHS GG&C Mental Health Service

Policy on meeting the communication needs of patients with dementia and their relatives and carers.

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Document Number:	**MHS 16**
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Approved by:	**MHS Clinical Governance Group**
Date approved:	**Dec 2022**
Date for Review:	**Dec 2025**
Replaces previous version: [if applicable]	Version 1 (2012)

1. Introduction and Background

This policy has been developed to guide staff in:

- The appropriate management of the communication support needs of patients with dementia.
- Meeting those needs, including having an identifiable and agreed relative's communication or participation strategy in place.

2. Scope

2.Background & Policy Context

2.1 The need for a policy on meeting the communication support needs of patients, and delivering effective communication with relatives, was highlighted in a report from the Scottish Public Services Ombudsman (case 201000373).

2.2 The policy is informed by the recommendations made in that report, and also by the following legislation and policy documentation:

a) The Standards of Care for Dementia in Scotland (2011), which is an action to support the change programme for Scotland's National Dementia Strategy.

b) The Adults with Incapacity (Scotland) Act (2000) [AWI Act].

c) Rights, Relationships and Recovery: The national review of mental health nursing in Scotland (2006).

d) The Mental Health (Care and Treatment) (Scotland) Act 2003 [Mental Health Act]. With particular reference to the underlying principles of respect for carers and participation.

e) Connecting People, Connecting Support: Transforming the allied health professionals' contribution to supporting people living with dementia in Scotland, 2017-2020 (Scottish Government, 2017).

f) The Healthcare Quality Strategy for NHS Scotland (2010).

g) Scottish Mental Health Law Review (2022)

2.3 Dementia Standards of Care

Of particular relevance are the following points taken from the Standards of Care for Dementia:

1. People with dementia will have their individual needs, preferences and aspirations met.
2. Service Providers will ensure the following.

a. That care plans are person centered and that efforts are made to maintain the relationships, natural supports and routines that are important to the person with dementia.

b. That systems are in place to collect and share information from the person with dementia and/or their carer about their personal preferences, choices and expectations of the service.

c. That staff are aware of whether the person with dementia has appointed someone as their welfare Power of Attorney or if there is a Welfare Guardian.

2.4 AWI Act

The AWI Act introduced a system for safeguarding the welfare and managing the finances and property of adults (age 16 and over) who lack capacity to act or make some or all decisions for themselves because of mental disorder or inability to communicate due to a physical condition. It allows other people to make decisions on behalf of these adults, subject to safeguards. The main groups to benefit include people with dementia, people with a learning disability, people with an acquired brain injury or severe and chronic mental illness, and people with a severe sensory impairment.

The Act aims to ensure that solutions focus on the needs of the individual: for example, a person with dementia may be able to decide what sort of support he/she would prefer to help with day to day living, but be unable to manage his/her money. In such a case a financial intervention may be all that is needed. In other circumstances a combination of welfare and financial measures may be necessary.

It is important that people with dementia and their carer's experience a person centred approach to support and care and that:

1. The person with dementia and their carer are supported to make decisions that put them in control of the care and support they receive.

2. Where a Section 47 (1) certificate is completed, i.e. When the patient is defined as incapable of consenting to medical treatment, then the practitioner should ascertain whether it would be reasonable and practical to seek the consent of a proxy with welfare powers, i.e. a guardian or welfare attorney. Any decision must take account of the present and past wishes and feelings of the adult as far as they can be ascertained by discussion with the person. However, the AWI Act also states that, where the person is unable to discuss this because of communication difficulties, then other ways of communicating must be explored.

The person who issues the Section 47 certificate will also need to take account of the views of the nearest relative or anyone nominated by a Sheriff and primary carer in so far as it is reasonable and practicable to do so and of anyone with an interest in the welfare of the adult. However, this does not require the practitioner to go to undue length to seek out such people. The code of practice states that it “would be good practice to make enquiries of the adult’s visitors, social work officer or other personnel currently involved with the adult and make such contacts with the relatives as are reasonable and practicable in the circumstances”.

2.5 Rights, Relationships and Recovery

The National Review of Mental Health Nursing identified the unique qualities of mental health nursing practice, and highlights the importance of mental health nursing practicing within a values and rights based philosophy. It provides action points for all health boards in Scotland to achieve, at the heart of which is relating to and communicating with service users and carers. Service users and carers are placed at the centre of nursing care, and their views of the care they receive form an integral part of nursing practice.

For persons with dementia as a result of impaired mental ability it is appropriate for general medical and nursing staff to seek guidance from Liaison Psychiatry and or a nominated Mental Health Liaison Nurse.

2.6 Mental Health Act

The Mental Health Act code of practice sets out principles that require to be followed in considering a decision or course of action. It states that the following should be taken into consideration:

a. The present and past wishes and feelings of the patient.
b. The views of the patient’s named person, carer, and any guardian or welfare attorney.
c. The participation as fully as possible of the patient in any decisions being made. This includes helping the patient to communicate where necessary.

d. The range of options available in the patient’s case.
e. The importance of providing maximum benefit to the patient.
f. The need to ensure that the patient is not treated any less favourably than the way in which a person who is not a patient would be treated.
g. The patient’s abilities, background and characteristics.

The Mental Health Act also states that except where a decision is being made about medical treatment, the principles also require that the needs and circumstances of the patient's carer and the importance of providing such information to any carer as might assist the carer to care for the patient, so far as it is reasonable and practical to do so, must also be taken into account. When considering the information to be shared with the carer, it is good practice to consider the patient’s right to confidentiality before information is supplied.

2.7 Connecting People, Connecting Support

Connecting People, Connecting Support is a national, three year policy document which presents an evidence informed case to support an approach to practice for all Allied Health Professionals working with people living with dementia. It highlights the role of Speech and Language Therapists in maximising the psychological wellbeing of people with dementia though providing personalised communication assessment and intervention. Where communication breakdown occurs, speech and language therapists may carry out a range formal and informal assessments and interventions to identify ways to maximize communication between the individual and their communication partners. SLT often provide training and support to formal and informal carers to ensure any strategies are understood and implemented. This allows each individual the potential to engage with their environment and community and be a valued and active participant in their daily lives as well as in their care. SLT findings will contribute to diagnosis, care planning and development of individualized communication strategies. 2 of the ambitions of Connecting People, Connecting Support are enhanced access to AHP-led information and partnership & integration of pathways of care, aiming to ensure timely access to SLT interventions using a personal outcomes approach to care.

2.8 Healthcare Quality Strategy

More generally, the Healthcare Quality Strategy builds upon the Scottish Government’s Better Health, Better Care Action Plan (2007) which made a series of commitments to improve the quality and experience of healthcare for patients and their carers. Services as part of the NHS are required to demonstrate their commitment in achieving the aims of these strategies by providing:

a. *Caring and compassionate staff and services.*
b. *Clear communication and explanations of treatment and conditions.*
c. *Effective collaboration between clinical staff, patients and carers.*
d. *Continuity of care.*
e. *Clinical excellence.*

This policy aims to meet the ambitions of the Quality strategy of a “Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making”.

Care planning and the collaboration with patients and carers is required to be documented in a patient’s care plan. Care planning and other standards of care both within hospital wards and community settings are subject to regular audit. These standards include a specific standard (standard 5) which is ‘Communication and engagement with users and carers. This standard should be monitored and quality assured every 3 months in every inpatient ward and every community team.

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3. Policy Statements

2. Policy Statements

3.1 Taking the above legislation and reports into account, the Health Board will apply the following policy on the communication needs of patients with dementia and their relatives and carers. The presence of dementia and indeed incapacity does not mean that the patient does not have some ability to comprehend and agree or otherwise to a course of treatment.

1. All patients admitted to hospital within the Health Board area where a diagnosis of dementia is made will have an assessment of cognition within 72 hours of admission; ideally earlier as part of the admission process. See Appendix 1 for AWI Act flowchart.

2. Where a patient is admitted to a general hospital ward but is already known to Community Older People's Mental Health Services, relevant information should be sought and shared including any prior assessment/diagnosis of dementia.

3. On general hospital wards, referral to the Older People's Mental Health Liaison Service should be considered for patients with complex presentations where there is difficulty in determining cognition and/or capacity.

4. Capacity will be regularly reviewed as part of multidisciplinary team meetings, and will be assessed against any decisions requiring to be made around treatment, with outcomes clearly documented.

5. Patients' communication support needs will be as certained during the admission process, including where appropriate through discussion with relatives/carers. Identified communication support needs will be documented (for example, use of short sentences to aid understanding; offering simple choices through photos) and staff will offer support for communication in line with these identified needs.

6. Staff will ensure that the guidelines within the Accessible Information Policy are followed when communicating with patients and their relatives/carers see http://www.staffnet.ggc.scot.nhs.uk/INFO%20CENTRE/AIP/Pages/Default.aspx

7. Where appropriate, advice will be sought from hearing impairment services on assessment of hearing and/or hearing aid supply/management.

8. If the patient has limited capacity, steps will be taken to make use of whichever skills remain to try to ascertain the patient's views of treatment.

9. This will be documented in the care plan.

10. Where a patient is deemed to lack the capacity to agree to a particular course of treatment, a Section 47 (1) certificate under part 5 of the Adults with Incapacity (Scotland) Act 2000 will be completed.

11. The past and present views of the patient will be ascertained as far as possible before engaging in any course of treatment, and staff will ensure that any wishes or preferences contained within an Advanced Statement or Advanced Directive are noted. Require the practitioner to go to undue length to seek out such people. The code of practice states that it "would be good practice to make enquiries of the adult's visitors, social work officer or other personnel currently involved with the adult and make such contacts with the relatives as are reasonable and practicable in the circumstances".

12. As part of this process, relatives' or other carers' views must be taken into account in deciding any course of treatment, and this will be documented.

13. It is a legal requirement to discuss treatments with any Welfare Guardian or holder of a Power of Attorney who has been appointed, and to take account of their views in determining the course of action. However in accordance with the AWI Act, essential treatment should not be delayed unnecessarily. Additionally, compliance with the principles of the Mental Health Act is important for detained patients. The general principles of AWI must be considered before any Section 47 certificate is issued. Therefore any proposed treatment must be likely to benefit the adult; the potential benefit cannot reasonably be achieved without treatment; and it must be the least restrictive option in relation to the freedom of the adult, consistent with the purpose of the treatment. This should include amongst other things, consideration of the duration of the certificate.

14. At the point of completing a Section 47 (1) form, relatives will be asked their view relating to the degree of participation they wish regarding treatment, and this will be documented. This may vary from wishing to know of any change of treatment at any time of night and day, to wishing a regular update on such treatment. In some cases relatives may choose not to be involved in such decisions but it is important that they are given this opportunity, and there is clear, documented, auditable evidence to support effective communication.

15. Relatives or other carers will be made aware of any multidisciplinary or clinical review meetings taking place, and will be invited to participate in decision making; usually by discussion with staff out with the meeting, rather than by direct attendance. However where there is a strong preference for

family members to attend a review meeting, this will be considered by clinical staff on an individual case basis.

16. Consideration should be given to involving Speech & Language Therapy Services where:

    a. *Patient’s speech/language functioning is difficult to ascertain and communication support needs are not clear.*
    b. *An in-depth assessment of speech/language functioning is required to support assessment of capacity.*
    c. *Advice is required on ways of maximising the patient’s residual communication skills.*

17. Particular opinions might well be held by relatives relating to treatment with sedating drugs for dementia, particularly antipsychotics. In view of this it is important to make every effort to discuss the use of antipsychotics with relatives or carers and to take into account their views and discuss the rationale for the use of such drugs. While the medical practitioner has the right to treat patients in a way that might be at odds with the relatives’ or carers’ views, this should not be undertaken lightly and the reasons for proceeding in this way must be discussed.

18. Where a patient with dementia does not lack capacity, consent of the patient must be taken into account when discussing interventions with relatives or carers. Assuming that such consent exists, it would be reasonable to have a similar level of discussion with relatives or carers as with those lacking capacity.

19. In communications with relatives, particular consideration will be given to the need to communicate information about the following specific issues:

    a. *The use of PRN medication.*
    b. *Food, Fluid and Nutrition [see separate policy].*
    c. *End of Life care.*
    d. *Prescription of antipsychotics.*
    e. *Restraint.*