

Antipsychotic drugs: what to do if you are worried

Alzheimer Scotland has been concerned for some years about the extent of the use of antipsychotics to treat some of the behavioural symptoms of dementia. We continue to lobby and campaign for a reduction in their use, while recognising that they can be helpful in some situations, if prescribed for as short a time as necessary and monitored appropriately. But if you are worried about a family member or friend who is receiving these drugs either in hospital or a care home, what can you do?

Sadly, this scenario is not uncommon. It has also been recognised by the Scottish Government¹, which is committed to improving care and reducing inappropriate use of antipsychotics.

What are antipsychotics?

The first tranche of antipsychotics (also known as neuroleptics or major tranquillisers) was originally developed in the 1950s. In the 1990s a new group of antipsychotics were developed which produced reduced side effects.

The main licensed use for antipsychotics is for the treatment of schizophrenia or bipolar disorder where there is psychosis. Antipsychotics are now regularly used for the treatment of restlessness, challenging behaviour and psychiatric symptoms common in people with dementia. One of these drugs (Risperidone) has recently been licensed specifically to treat severe and persistent challenging behaviour in people with Alzheimer's disease who have not responded to other therapies. The other drugs are used 'off license'.

How do I know which drugs are which?

Drugs can be called by their generic name or by the trade (or proprietary) name given by the manufacturer. The anti-psychotic drugs most often mentioned by callers to our Freephone Dementia Helpline are Chlorpromazine (Largactil); Haloperidol (Haldol, Serenace); Olanzapine (Zyprexa); Quetiapine (Seroquel); and Risperidone (Risperdal).

Other drugs which may be used are Amisulpride (Solian); Aripiprazole (Abilify); Fluphenazine (Modectate); Promazine (Promazine); Sulpiride (Dolmatil, Sulparex, Sulpitol); Trifluoperazine (Stelazine); Zotepine (Zoleptil); Zuclopenthixol (Clopixol).

Look at the packaging or ask medical or nursing staff which drugs are being prescribed to see if any are antipsychotics.

¹ Scottish Government, The Scottish Health Survey, 2015 Edition, Volume 1, A National Statistics Publication for Scotland, October 2016.

Side effects

Side effects from antipsychotics can include excessive sedation, dizziness, unsteadiness, and symptoms like those of Parkinson's disease (shakiness, slowness and stiffness of the limbs), chest infections, ankle swelling and falls. But recent research has raised concerns about even more serious side effects such as a higher risk of strokes and premature death, particularly if the drugs are given for long periods.

Antipsychotics may be particularly dangerous for people with dementia with Lewy bodies (DLB). If anyone with DLB is prescribed an antipsychotic they must be constantly supervised and the treatment reviewed regularly by a GP or consultant.

The side effects and risk of early death are even greater if antipsychotics are given alongside other sedative drugs such as diazepam or temazepam.

Whichever drug is used, treatment with antipsychotics should be regularly reviewed and the dose reduced or the drug withdrawn if side-effects become unacceptable.

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What the guidance says

Scottish guidance published in 2006 (the SIGN guideline²) states ***“If necessary, conventional antipsychotics may be used with caution [our emphasis], given their side effect profile, to treat the associated symptoms of dementia.”***

Also in 2006, the National Institute for Health and Clinical Excellence (NICE) published a dementia guideline³. A key recommendation of the NICE guidance is that people developing these distressing symptoms **should first be offered an assessment to try to establish any reasons for what is happening**. This assessment should consider:

- whether the person is in pain or in ill health
- the side effects of medication
- if the person is reacting to something (or someone) in their surroundings
- the person's past history such as their job or trade or their old routine.

The NICE guideline says that:

- antipsychotics should not be used as a treatment of first resort except where there is severe distress or immediate risk of harm to the person or others
- the medical team should discuss the possible benefits and risks of the treatment with the person with dementia and/or carers
- alternative medication should be considered such as one of the anti-dementia drugs or an anti-depressant
- the dosage should start low and only increase gradually if required

² Scottish Intercollegiate Guideline Network, 2006. Management of patients with dementia: a national clinical guideline. (Guideline 86).

³ National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, 2006. Dementia: supporting people with dementia and their carers in health and social care.

- treatment should be time limited and reviewed at least every three months
- records should be kept of the symptoms being treated and how they are affected
- records should also record changes in the person's cognitive abilities
- staff should be trained to anticipate behaviour that challenges and how to manage extreme agitation, including techniques for defusing a situation and safe methods of physical restraint
- violent behaviour should be managed without the prescription of high doses or combinations of drugs, especially if the person with dementia is elderly or frail.

Action to take

Information is power

Family members and friends know the person best and can help medical and nursing staff to understand them and what might trigger an adverse reaction. They can observe changes in the person's condition after receiving antipsychotics and bring these to the attention of staff.

Know your rights about medical treatment

There are legal safeguards applying to medical treatment for people with dementia. If a doctor believes that a treatment will benefit a patient with dementia who is incapable of consenting, the doctor should sign a certificate of incapacity under Section 47 of the Adults with Incapacity (Scotland) Act 2000 which gives him or her authority to treat the person.

Before doing so, the doctor should consult with the carer and anyone else closely involved with the person, to get their views on the person's ability to give consent. The doctor must record on the certificate the consent of a proxy (such as a welfare power of attorney or guardian) if there is one; or if there is no proxy, that the consultation has taken place with carers.

Both the proxy and the main carer have the same right to object to a proposed treatment and to use the procedure for dealing with disagreements. You can contact the Mental Welfare Commission to ask for a second opinion from a doctor from the relevant specialism. The second doctor must consult with you, the doctor and others with a close interest in the person. If the second doctor agrees with the first, then the treatment can go ahead. But if you still disagree you can go to the Court of Session for a decision.

If the second doctor agrees with you (the proxy/carers), then the first doctor must comply or can go to the Court of Session. An appeal to the Court of Session would require specialist legal advice and could be costly, although legal aid may be available.

Treatment without consent can still be given in an emergency without the need for a certificate of incapacity, in order to preserve life or prevent serious deterioration.

If the person is detained under the Mental Health Care and Treatment (Scotland) Act 2003, they can be given treatment for mental disorder without their consent (or without your consent even if you have relevant decision making powers) if they are subject to short-term detention or a compulsory treatment order. They cannot be treated without consent if subject to an emergency detention, unless the treatment is required urgently, or they are being treated under the Adults with Incapacity Act.

Raising concerns

If you are worried about the effect of antipsychotics or think that someone you care for may have been given antipsychotics without you knowing, you should discuss this in the first instance with the medical practitioner (consultant or GP) involved or the person in charge of the ward or care home. If you are not satisfied with the explanation or outcome, put your concerns in writing. It can help to keep a diary or record of your observations and the sequence of events (who said what and when).

Complain

Many people worry about complaining in case it makes things worse for the person with dementia but it's unlikely to get any better if nothing is said or done. Each hospital or care home will have a complaints procedure which they must tell you about.

Get help

Contact the Mental Welfare Commission. Their service user and carer freephone line **0800 389 6809** is open Monday-Friday, 9am-12pm then 1pm-4pm. The Commission will look into situations if they think that someone with a mental illness or learning disability is not getting the right care and treatment.

If the person you are worried about is in a care home, you may contact the Care Inspectorate, the body responsible for regulating care service providers and making sure that they meet National Care Standards on **0345 600 9527**.

In 2009, the Care Inspectorate and the Mental Welfare Commission produced a report, 'Remember I'm still me', which assessed at the quality of care for people with dementia in care homes. The report found that a third of the residents in the homes they looked at were receiving antipsychotics; there was evidence of inappropriate and multiple prescribing; a lack of regular reviews; and poor recording on personal plans.

Talk our 24 hour Freephone Dementia Helpline on **0808 808 3000**. The Helpline cannot take direct action on your behalf but it can help to talk through your concerns and discuss what steps to take next.