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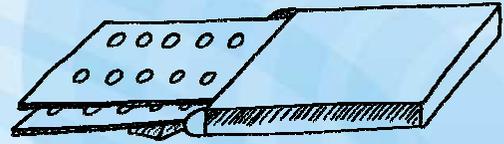
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The information in this leaflet was valid at the date of production **July 2018** and is due for review in **July 2020** Leaflet code: E-DCIL-08-189

Supporting people with learning disabilities with medication prescribed for dementia

An information leaflet for carers



Introduction

This leaflet has been written for carers and staff who are supporting a person with a learning disability who has been given a diagnosis of dementia.

You may have already been given a copy of the leaflet called “Dementia and people with learning disabilities: An information leaflet for carers”. If you have not received this leaflet, you may wish to ask a member of the community learning disability team for a copy. The leaflet “Dementia and people with learning disabilities” contains useful information about dementia, including what dementia is, what the symptoms of dementia are, and how the community learning disability team can help.

One of the ways the community team can help a person with a learning disability who has a diagnosis of dementia is by recommending medication when it is appropriate.

This leaflet provides information on:

- What medication is available for people with learning disabilities with a diagnosis of dementia
- How medication may help a person with learning disabilities who has a diagnosis of dementia
- What you need to know in order to support a person with learning disabilities to make a decision regarding whether or not they wish to take medication for dementia
- What you need to know in order to support a person with learning disabilities who is taking medication for dementia

What you need to know in order to support a person with learning disabilities who is taking medication for dementia

This section provides advice for carers of people with learning disabilities who have begun to take medication for dementia. As a carer of a person with learning disabilities, it is likely that you already support them to take medication for other health needs. Here are some general reminders about supporting the person that you care for which apply to taking medication for dementia:

- Support them to take their medication regularly and as directed
- Monitor the expiry dates on medication
- Support them to attend/be available for community team appointments (including blood pressure and pulse checks)
- Support them to inform their doctor or pharmacist that they are taking medication for dementia when they are prescribed any other medicines.

As a carer for a person with learning disabilities who has been diagnosed with dementia, it is likely that you are already used to monitoring changes in the person you care for. These skills are central to identifying possible side effects of medication, as well as monitoring further changes over time that may be related to dementia itself.

- If you notice any possible side effects of medication for dementia inform the community team and/or the person you care for's GP. Page 7 of the leaflet “Tablets for Dementia” provides space for you or the person you support to write down any changes or symptoms you have noticed.
- The community team monitor changes over time in the skills and abilities of people with dementia. You may be asked to help by answering some questions about the person you care for and any changes you have noticed.

Useful things to know to support a person with learning disabilities to make the decision whether or not to take medication for dementia

If you have been given a copy of this leaflet by a member of the learning disability community team, this means the team psychiatrist thinks that medication for dementia could be helpful for the person that you support. Dementia medication is typically taken once a day in tablet form and usually at night time. If a person decides to begin taking dementia medication, their blood pressure and pulse will be checked by a community nurse. How frequently these checks are undertaken depends on an individual's medical history and health status. As with most medications, there are some side effects experienced by people taking medication for dementia.

The most commonly reported side effects are:

- Diarrhoea
- Vomiting
- Fatigue
- Nausea
- Muscle cramp
- Insomnia

Some other side effects have been reported by people taking medication for dementia and a complete list is given on the further information sheet accompanying this leaflet. It is important that you read this complete list. Also, as information regarding medications is regularly updated, it is important that you consult the most up-to-date sources of information. Please refer to page 5 of this leaflet for information on how to do this or ask a member of the community team.

In order to support a person with a learning disability to make as informed a decision as possible about whether to take medication for dementia, it is important that the person understands what this would mean for them. As a carer, you play an important role in making sure that the person you support is given the information in way they can understand and is appropriate to them. As with any significant decision, it is important that the person is given time to make sense of the information provided to them. Encourage the person you support to explore pros and cons as far as is possible.

Using this leaflet

This leaflet can be used:-

1. Alongside a leaflet for people with learning disabilities called "Tablets for people who have Dementia".
2. As a stand-alone source of information for carers of people with learning disabilities.

If the person you care for has not been given a copy of the leaflet "Tablets for people who have Dementia", don't worry, it is not appropriate for all people with learning disabilities. [However you may wish to skip ahead to page 5.](#)

Using the leaflet "Tablets for people who have dementia" with people who have learning disabilities

The leaflet "Tablets for people who have Dementia" is designed for people with a learning disability with a diagnosis of dementia. The leaflet is designed to provide information to enable people with a learning disability to decide whether to begin taking medication for dementia. For those people with a learning disability who do decide to take dementia medication, it also designed as a source of key information that can be referred back to.

The leaflet "Tablets for people who have Dementia" is designed to be not just an information leaflet but to be used as the basis for an **interactive activity**. The leaflet should be given out along with some **stickers** that allow the person with learning disabilities to personalise the leaflet so that it is directly relevant to them. There are also spaces to **fill in gaps** and **add personal information**.

It is intended that a person with learning disabilities will be supported by their carer to go through the leaflet and personalise it. The leaflet is also designed as a resource that people with learning disabilities can revisit and look over again with their carers.

Hints and tips for using the leaflet “Tablets for people who have dementia” with people who have learning disabilities

- Make using the leaflet with the person you care for as interactive and engaging an experience as possible. Help them to put the stickers of their doctor and the place they attend for appointments in the appropriate spaces. If possible, support them to write in names, dates and other personalised information in the appropriate gaps. If this is not possible, maintain engagement by asking/explaining to them what should go in the gaps.
- Go through the leaflet with the person you care for at their own pace. It may be enough to go through a page or so at a time. Revisit the key points before moving on to give them new information. As a carer, you know them well, so you can use their own language to explain the key ideas and facilitate their understanding.
- Use the leaflet as a starting point for wider discussion. For example, the person you care for may need to talk more about what dementia is before they can make a choice about medication for dementia. Encourage them to ask questions. If you need more information to answer these questions, you can use the space on page 7 to make a note of this.
- Support the person you care for to understand and remember important information by revisiting the leaflet often. For example, you can look at the leaflet together again before appointments with the doctor. This ensures that any important questions can be asked or any important information passed onto the doctor. Again, there is space on page 7 to make notes.

What medication is available for people with learning disabilities who have a diagnosis of dementia?

The medication used to treat the symptoms of dementia in people with learning disabilities is called Donepezil. The most well-known trade name of this medication is Aricept. This medication is given in tablet form.

This leaflet provides a summary of some of the information regarding Donepezil (Aricept) medication. However, information regarding medications is regularly updated and it is important that you consult the most up-to-date sources of information.

You should find a *further information sheet regarding Aricept medication accompanying this leaflet*. If you have not received this additional sheet, please ask a member of the community team for a copy.

As information regarding medications is regularly updated, below is an internet address for information regarding Donepezil (Aricept) medication. You can type the following into your web browser:

<http://emc.medicines.org.uk>

...and then type “Aricept” or “Donepezil” into the search box.

How medication may help a person with learning disabilities who has a diagnosis of dementia

Medication cannot cure dementia but can help to slow down the progression of dementia and help ease the symptoms, for example, helping to stabilise deterioration in memory.