Dementia and Prisons: Roundtable notes

Seldom heard groups

People from seldom heard groups face barriers to accessing good health and social care, which at times fails to meet their needs. Challenges can include a lack of awareness and cultural understanding across health and social care settings. This problem has become more acute as public service budgets have been cut.

Through our diverse membership the NDAA is well placed to improve this situation by harnessing the resources and ideas of our members and of other organisations operating across health and social care.

In June 2017 the NDAA hosted a series of evidence gathering roundtables with leading stakeholders involved in delivering care and support of seldom heard groups. The roundtables covered dementia and learning disabilities, dementia within prison settings and within the LGBT+ community.

Introduction

Dementia is a growing problem within prisons. Prisoners over the age of 60 are the fastest growing age group in prisons, with the latest figure standing at 10,000. This number is set to increase unless there are major changes in sentencing trends. There is currently no national plan for older prisoners, but action is needed. There is still limited understanding of the needs of older prisoners in England and Wales. As the number of older prisoners rises, so too will the prevalence of dementia.

Roundtable

20 people came together on 13th June in London to discuss the key issues and actions to be taken around supporting people affected by dementia in prisons. The NDAA hosted this four-hour roundtable, which was chaired by Phil Freeman from the NDAA. The attendees consisted of experts on prisons and dementia. The session consisted of small group discussions around the issues and agreeing on actions that this campaign could focus on for NDAA members to undertake.

The key themes from the prison roundtable discussions are detailed within this document.

Key themes

1. Pathway

The pathway to care is key. There needs to be more focus on diagnosing people in prisons as awareness of the condition is low. It is vital to know what happens to a person once they have been diagnosed with dementia, whether before they enter prison, or during their time there. Due to the quick churn of prisoners there often isn't the time to recognise changes in behaviour which could lead to a dementia diagnosis. Symptoms are more noticeable if a prisoner has been in prison for a longer period of time; short term sentences mean

symptoms can be missed. There are differing pathways and these need to be standardised, along with a promotion of basic information around dementia and the needs of the prisoners. There needs to be more clarity around how the Care Act translates into practice and how this integrates with the Care Act. The pathways need to be linked in with Local Authority and healthcare pathways, as current screening and assessment tools are inadequate. There is no meaningful assessment in the first instance when a person enters a prison. There is a need for a secondary assessment around cognitive impairment. There also needs to be an emphasis on transition in and transition out of prisons and between prisons. Prisons and prison healthcare teams need to demonstrate what systems they have in place to ensure prisoners with memory problems are identified and receive a diagnosis.

2. Engagement and Information sharing

Information sharing is vital to the care and smooth transitioning of prisoners. Prisoners can often be moved from one prison to another before the information has been moved with them, making the journey more confusing. If prison staff do not have the appropriate information this is detrimental to the person with dementia and the staff around them. More engagement is needed with the Department for Communities and Local Government, particularly around the provision of housing for ex-offenders. Upon release ex-prisoners need to be protected as they can become targets. It can be difficult to find housing packages at short notice. Prisons need to be everybody's business and require multi-disciplinary teams to address their needs. Connections between community services and prisons need improving.

3. Training

Diagnosis is necessary for the benefit of prisoners and prison staff, however there is a lack of training amongst prison staff meaning dementia often goes unnoticed and therefore undiagnosed. Awareness raising is important and staff need more training which will help them to identify when a prisoner is presenting symptoms of dementia or other forms of cognitive impairment, and when to refer to prison healthcare teams. There needs to be a greater emphasis on recognition and identification in the first instance and then a rolling training programme for 2-3 years to embed the practices. There are not enough staff in the system and all staff need to be exposed to mental health training.

4. Existing legislation, initiatives and good practice

Following the Care Act local authorities have a statutory responsibility for the health and social care needs of prisons, however there is still uncertainty around this. The prison sector needs to develop an understanding of the Care Act, as it places responsibility on local authorities for prisoners within their boundaries, for example, if a person from a local authority is sentenced and goes to a prison in another local authority it can cause confusion over who has the responsibility. Better awareness and understanding of the Mental Capacity Act would also help identify prisoners with cognitive problems including dementia. When a social worker is assigned to a prison, this works well and when they are assigned to a cluster of prisons this tends to lead to a more co-ordinated approach. Working with occupational therapists also leads to more effective results.

Offender Personality Disorder Pathway (PIPE) – This model has worked at Pentonville and can be used to transition money from health into other areas.

Isle of Wight (IoW) has two prisons with a memory service pathway and pick up on referrals, predominantly health and social care. The Head of Equalities is looking to link up the two. IoW have a well thought out and functioning pathway.

Peer to peer support schemes are working well at Whatton, Devon, Staffordshire and Lancashire. At HMP Franklyn, they are working with the Alzheimer's Society point of advice service and looking to implement a pathway. Prison buddying is an effective way of improving health outcomes. Recoop have seen good practice, including buddy systems and prisoner support.

5. Future provision

There is a variation in provision across the country and a need for prevalence data across prisons. Data is being accumulated through a University of Manchester project. Governors are key to the provision of effective care for people with dementia, however they are also under increased pressure and time and resource restraints. At present there is no national strategy for older prisoners. A strategy is needed to align all prisons and have a basic set of standards for prisoners with dementia.

Recommendations

The NDAA is asking organisations to sign up to a pledge and to take actions to support people with dementia in a prison setting. These recommendations are to be sent to all prison governors in England. Areas we discussed at the round table were:

- The need for an older persons strategy
- A top tips, easy read document
- The need to have the backing of prison governors
- Early diagnosis needed along with person centred care
- Knowing what the minimum standards should be
- Pathway of care is a priority
- The need for accurate data
- Promotion of existing work

1. National strategy for older prisoners

- There is no national strategy for older prisoners. A strategy would be key in formulating a clear pathway for all prison governors to follow and to give a clear direction
- We call for the strategy to encompass older people, dementia and disability (especially cognitive impairments)
- The strategy would lead on to supporting the other recommendations the NDAA are making

2. Top tips booklet

- This booklet, or one page of top tips would be a quick and clear reference for prison officers
- Top tips could help identify need and refer a person to the appropriate healthcare they need
- It would include how to identify if a prisoner had a memory problem or other cognitive difficulties and what actions to take
- The Alzheimer's Society prison project staff are working on introducing this into prisons

3. Importance of early diagnosis, pathway of care and joined up working

- It is important to see the person not the dementia
- When changes are noticed, this needs to be acted upon quickly and timely but accurate differential diagnosis should be received
- Diagnosis is followed up and the relevant professionals are involved at the appropriate times
- Diagnosis flags a need for joint working with health and social care professionals
- A consistent pathway of care needs to be established throughout the system (this links in with recommendation 1 – National Strategy)
- Work is needed in parallel with all areas including, Local Authorities, prison governors, head of healthcare

4. Training

- Training needs to be available to help staff identify when a prisoner is presenting symptoms of dementia or other forms of cognitive impairment. Awareness sessions for fellow prisoners is also needed
- There needs to be a greater emphasis on recognition and identification in the first instance and then a rolling training programme for 2-3 years to embed the practices with all staff
- Working with community groups to bring specialist knowledge and training into the prison system

5. Data

- It would be useful for prisons to have a mechanism for gathering and sharing information to support a better understanding of dementia
- There is a need for prevalence data across prisons
- There is a study being undertaken by the University of Manchester, which would be beneficial for all prisons

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