Supporting people with complex personality disorder

Your chance to shape care for the future

Consultation: 20 April to 27 July 2009
Shaping care for the future

The NHS wants to provide safe, good quality care that everyone can use. Any time there might be an important change to health services, the NHS asks local people, families and organisations for their views. This helps the NHS decide what to do next.

The NHS is asking for your views about services for people aged 18 or older with complex personality disorders.

This document describes what a complex personality disorder is, the type of care currently available, why care needs to change and how services could be organised in future.

There is much more information available on the consultation website: www.westkentpct.nhs.uk or by post.

See page 13 for contact details

Any changes will affect people with personality disorders and their families, carers and friends living in the East of England, London, South Central and South East Coast regions.

There are already some services available for people with personality disorders, see page 4, but we are not focusing on any individual service or building. We are looking at the best ways to organise care throughout the whole area to meet people’s needs.

Your ideas will help the NHS decide how to support people best.
What is personality disorder?

Our personality is what makes us a unique person. It includes our approach to life and how we think, feel and react to others. People who are different to society’s views about what is ‘normal’ are sometimes said to have a ‘personality disorder.’

About one in ten people have a personality disorder. Most are able to live well day to day. A much smaller number have a complex personality disorder which makes it difficult for them to live life well and can cause problems for themselves and their families.

People with complex personality disorders do not usually hurt other people, but they sometimes harm themselves as a result of the very distressing feelings they experience. For example they might get angry, feel very depressed, misuse alcohol or drugs, have an eating disorder, not always look after themselves or try to commit suicide.

What care is available now?

The NHS uses the terms ‘Tier 1’ to ‘Tier 6’ to describe the types of services for people with personality disorders. Tier 1 services are for people with the least serious disorders and Tier 6 services are for the most serious.

For people with mild to moderate personality disorders the NHS offers Tier 1 to 3 services in local communities, including support from GPs, community mental health services, nurses and voluntary groups and specialised day centres. People with more severe or complex personality disorders might need some extra care and are offered Tier 4 specialist services. People with personality disorders who are at risk of harming others are offered Tier 5 or 6 services in hospitals or other secure facilities. People will move from one tier of service to another as their needs change.

This consultation is about how to provide the best care for people with complex personality disorders who might use ‘Tier 4’ services.

More information: the consultation website has a review of research and an assessment of the number of people who might be affected.
There is no simple description of a person who might use Tier 4 services or the type of care they might need, but we can give you some general ideas to help you understand the type of care we’re talking about.

Someone who uses Tier 4 services might:

- have been told they have ‘complex or severe personality disorder’ (throughout this document we use the term ‘complex’ to mean complex or severe)
- find it difficult to relate to others which could affect their personal and family relationships and work
- have impulsive behaviour or be at risk of hurting themselves
- have a history of misusing alcohol or drugs
- have been admitted to mental health hospitals a lot or had long stays in mental health hospitals

There are services available in the community to help people cope with their personality disorder, and more specialised services to provide extra care. The important things that any Tier 4 service should be able to do include:

- helping to find out what the problems are (assessing people)
- providing treatment, care and support for people who need more help than is available from local services (throughout this document we use the term ‘care’ to mean treatment, care and support)
- offering support and training to families and carers
- helping people find and use local services to meet their needs
- providing training and support to other health and social care professionals to help them provide the best care too

More information: the consultation website has a description of the essential parts of Tier 4 services.
At the moment, Tier 4 services for people throughout London, the East of England, South Central and South East Coast regions are provided by two residential or ‘live in’ services in London called the Cassel Hospital in Richmond and the Henderson Hospital in Sutton. The Henderson Hospital is temporarily closed. The NHS also uses services run by the independent sector, especially if there are no spaces available at NHS hospitals or if NHS services don’t fit the person’s needs.

People with a complex personality disorder might go to live at these services for several months and receive treatment and support every day. (Throughout this document, we describe these types of residential services as ‘live in’). There are 44 spaces for people spread across these two locations. When people stop staying at the live in facility they can continue to receive treatment and support for months or years afterwards. This is sometimes called outreach support.

At the moment, we estimate that the cost of NHS Tier 4 services and other extra placements in the independent sector is probably at least £10 million per year. We are finding out more about costs – see our website for the most up to date information.

The NHS wants to know how Tier 4 services should be provided in future. We are looking at whether the model of outreach support in the community with some ‘live in’ care is the best, or whether other approaches or combinations might be better. We are also looking at how many live in units and spaces there should be.

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The NHS is not asking about the good and bad points of the services at the Cassel and Henderson Hospitals. We know that many people who use these services value them very much and that people who work at these services care passionately about the work they do. We’re looking at what people from throughout the four areas need and the best way to organise care to meet those needs.

We are not looking at the exact type of treatments provided by different services – just whether there should be more outreach care and how many live in units might be needed.
Why change?

There are five main reasons why it is important to think about change.

1. New services are starting

In the past, live in services were the only type of care available for people with complex personality disorder. In 2003 it became government policy to create a full range of Tier 1-6 services to support people with personality disorders in the community and in live in facilities. Since then, services have been set up to help people with less severe personality disorder closer to their home. This means the NHS has to think about what type of live in services, if any, might be needed to complement the local services being set up.

2. Current services can’t meet all needs

The Tier 4 services provided at the Cassel and Henderson Hospitals are both ‘therapeutic communities.’ This means the therapeutic environment itself is one of the main ways of bringing about change, alongside intensive therapies. Members of the live in community have a key role in making decisions about the everyday running of the service. The relationships between people using the service and staff help people improve their ways of relating to others.

Therapeutic communities work well for some and many people have told us how good the services are. But the ‘therapeutic community’ approach might exclude people who do not work well in groups or do not feel they fit in with other group members. A national review (see below) suggested that other approaches might be needed to make sure a wider range of people can get help.

The NHS wants to treat everyone fairly and make sure that people’s human rights are respected. When we talked to people using services, professionals providing services and NHS managers we found that current services might not be meeting all needs and, without meaning to, might exclude some people. For example, people with children, young adults and people from minority ethnic groups might find it more difficult to access services or might not be as comfortable using services. People who feel they are different to other people in therapeutic communities might also find it harder to fit in. We need to think about whether there are other ways of organising services to make sure that vulnerable groups are included. For this reason, the NHS needs to think about what other types of care might be useful. We need to build a range of therapies and treatments, perhaps in addition to therapeutic communities, not instead of them.

More information: The National Specialised Commissioning Group’s 2008 review is available on the consultation website.

More information: You can see our initial ideas about how change might affect different groups on the consultation website.

See the ‘have your say’ section of www.westkentpct.nhs.uk
3. Services might be far from home

The NHS aims to provide care as close to home as possible, although it can sometimes be helpful for people to receive care away from their local area too.

For the East of England, London, South East Coast and South Central regions, all specialist care is currently organised around two live in facilities in London. This might be a concern because general research suggests that people want services offered close to where they live and people might be more likely to use health services when they are closer to home.

For people with personality disorder services, it is especially important to have good follow up and outreach care, because it means that people can go home earlier and get ongoing help once they return home. Having services closer to where people live might help to make this outreach support more accessible.

We need to think about ways of organising care so that people living further from London get good support too.

4. Current ways won’t last long term

The way care is organised needs to be able to last long term or be ‘sustainable.’ Current services might not be able to last long term.

Now that more local services are being set up and the way that services are paid for is changing, Tier 4 services are seeing fewer people. This does not mean that there is not a need for these services, just that fewer people or different types of people are using them than before.

Those who do use the services are much more likely to have more serious needs than before, when community personality disorder services did not exist to help.

These changes affect current services because:

- The ‘therapeutic community’ approach might work best when there are enough people for the environment to be therapeutic. If there are not enough people, then the community cannot do all the activities that help people.

- If people with more severe issues than before are using the services, the way the community works and how people interact with each other changes. This may mean that care is less helpful.

- If there are fewer people using the services, the services get less funding (money goes to whatever services people are using). Without enough funding, the services can’t survive. There is no fixed or predictable income to keep the live in services going.

These changes mean that current services are not stable and cannot be sure of their future. We need to organise care so that services have more stability and reliable funding.
5. Guidelines have changed

Previously it was not always acknowledged that personality disorder was treatable, but changes to government policies and the law mean that the NHS now recognises that people with personality disorder do benefit from supportive care. The NHS aims to provide ‘appropriate medical treatment’ for people with complex personality disorder. The appropriate care might not be a hospital or live in service. The NHS has to follow new guidelines and think about other ways of organising care, perhaps in addition to live in services. Providing a range of care is important, including outreach care.

There is no strong evidence base about how many people might need Tier 4 services, what models of care are best, or what type of changes might be needed. But national guidance is clear that people with personality disorder should not be excluded and should receive good quality care.

To summarise, we cannot keep things the same as they are because:

- new services are starting in the community so we need to think about how everything might work together
- current services might not be meeting all needs so we need to think about other possibilities
- sometimes there are not enough people using services
- people outside London might be getting less support and it might be better to offer care closer to where people live
- if there are fewer people using the services, the services get less funding so might not be stable in the long term
- changes to the law mean we should think about the variety of approaches available

If no change is made then services might continue to be unstable and would not be certain of their future. The care available would not meet the needs of all people with complex personality disorder and some groups would continue to be disadvantaged.
Possibilities for the future

The NHS wants to make care available when and where people need it and to make sure the services will be stable in the long term.

In 2008 and 2009 we have been reviewing current services and thinking about next steps. We worked with people using services now and in the past, family members, voluntary groups, professionals providing services, the organisations that pay for services and other interested organisations and professionals to come up with new ideas. We ran workshops with professionals and service users, set up an advisory group made up of people using the services and family members, minority ethnic group representatives, professionals providing care, and managers, and talked to people from all four areas.

We are recommending more focus on providing outreach care in the community plus four possible ways of organising live in services – you might be able to think of other approaches and we would be glad to hear them.

A possible new approach

A suggested change from the current approach is to have special ‘outreach teams’ in the community. These outreach teams would help find people who might need Tier 4 services, signpost people and families to appropriate care, train the people running local mental health services, and offer follow up care. This is a real change from the present, where most specialist services focus on live in care. We are very eager to hear your views about whether having outreach teams is a good idea.

As well as having outreach teams in the community, we looked at how many live in facilities might be needed. About 100 people each year currently use these type of services. An advisory group came up with four options. The following pages describe each option for the live in units, and some of the possible pros and cons. You might be able to think of other positive and negative points.

More information: on the consultation website you can see how we worked with people using and running services to come up with possible options.

More information: you can see how we worked out the cost of each option and more information about possible pros and cons on the consultation website.
Having no live in treatment units

In this option, there would be no specialist live in Tier 4 treatment unit for personality disorder in the four regions. Most of the specialist care for people with complex personality disorders would be provided by new community outreach teams, working with services designed for people with less severe needs.

There would be one specialist outreach team for London, one for the East of England, one for South Central and one for the South East Coast. These outreach teams would be hosted by local community services and each area would be responsible for developing their own service. There would also be more local services developed to provide intensive day and outreach treatment in each of the four regions, but these would not be live in (residential). Everyone would be treated in their local area.

In a crisis when people could not safely be cared for within an outreach or day programme, they would be admitted to their local acute mental health hospital. There would be access to beds outside of the area on a short term basis to provide care for people and their carers.

There would be social care crisis facilities and access to support 24 hours a day, for example from Community Mental Health Teams, Home Treatment Teams and hostels.

This option would cost about six million pounds per year. We think current approaches might cost at least 10 million pounds per year, spread throughout the four regions.

Some possible positive points

- The focus is on supporting people close to home
- There is no live in unit so this might be the quickest option to get started
- This might be the cheapest option to put into practice straight away
- Outreach teams would be based in local communities and each local area would develop the service to meet their own needs
- All four regions would have similar access to support rather than one or two areas getting more benefit

Some possible negative points

- There must be good services in the community for this option to work well. Currently not all areas have these local services set up
- People might have to use acute mental health units or hospitals if there is nowhere else to go
- There might be extra costs if people have to use other hospitals or services
- If outreach teams have a lot to cope with they might not find people with extra mental health needs or be proactive in identifying people who need treatment
- This option might place more pressure on local services and community mental health teams and there might not be enough staff or resources
- Existing community services might not have all the specialist skills needed for people with complex personality disorder
Having one live in unit

In this option, there would be one specialist live in treatment service covering all four regions. This would be quite a large unit and provide between 20-30 places at any one time.

There would be specialist outreach teams for each of the four regions, who would assess and refer people to the live in unit. The four outreach teams would all be linked to the same live in service.

The outreach teams would provide follow up care when people leave live in services and make sure that local services offer the support that people need.

There are no plans yet about where the service would be based. This option would cost about six or seven million pounds per year.

Some possible positive points

- There will be some live in services available
- There will be fewer beds or spaces than at present. This might mean that local services develop other types of care rather than relying only on live in units
- The four outreach teams will be responsible to a central hub, giving them an opportunity to share ideas and get support from each other
- Having one unit might provide more consistency as things would be done in the same way for people from all four regions
- Based on the number of people currently asking to use Tier 4 services, this option might provide about the right number of spaces to be stable in the long term

Some possible negative points

- The live in service would be quite far away from home for many people
- Outreach teams would be quite far away from the live in unit which might make communication more difficult
- It might be hard for one service to support people with many different types of needs
- There might be fewer live in beds compared to now
- People who live nearby might get better access to care, which would not be fair to those living further away
- There might be less patient choice with only one unit
- A new building or building alterations might be needed
Having two live in units

In this option, there would be two specialist live in services covering all four regions.

These two services would each provide different treatment programmes to meet a wider range of people’s needs.

Each service would provide about 15-20 places.

There would be specialist outreach teams for each of the four regions, with the two live in services acting as a central contact point. The specialist outreach teams would refer people to the most appropriate of the two services and provide follow up care.

There are no plans yet about where the two services would be based.

This option would cost about eight million pounds per year.

Some possible positive points

- There might be similar numbers of spaces available as there are now
- There might be more choice for people using services
- The distances from home might be reduced if the units were located in different areas
- Two outreach teams would be responsible to each service so the teams could support each other and share ideas
- Each of the live in facilities could take a slightly different treatment approach in order to meet different people’s needs. For example, one unit might provide a specialised women only service.

Some possible negative points

- There might not be enough people using services to keep two services stable and well funded
- The NHS would have to invest money, and lots of different organisations would have to agree to this
- The areas where services are located may have an unfair advantage over areas without a unit
- The services might compete with each other rather than working together
Having four live in units

In this option there would be four specialist live in services for people with complex personality disorders, one in each of the four regions. There would be between 10-15 beds in each.

There would be a specialist outreach team in each region to provide follow up care and make sure people receive help from local services. The specialist outreach team would work closely with local services and find out which people might need live in care.

This option would cost about 12 million pounds per year. We think that the current cost of care might be at least 10 million.

Some possible positive points

- There would be live in services in every region
- This may reduce travel to services
- Each unit could take a different treatment approach, making a wider range of care available
- There would be more choice for people using services
- Outreach teams would be near to the specialist live in service and near to local communities
- Each region would have more equal access to support for people with personality disorders

Some possible negative points

- This is the most expensive approach of the four options
- The NHS would have to invest money, and lots of different organisations would have to agree to this
- Some units might be too small to use some treatment approaches (for example the ‘therapeutic communities’ approach might need more people)
- Instead of developing community services, we might rely more on live in services because they would be available in each region
- There may not be enough specialist staff to cover four units
- There may not be enough people using services in each area to keep the services well funded and stable
Have your say

The NHS wants to hear your views about how services for people with complex personality disorder should be organised.

The consultation is not a referendum, so the option with the most support will not necessarily be chosen. Instead, the NHS is interested in knowing the good points and bad points about every option, to help make a well rounded decision.

You can have your say by:

- completing our online survey on the ‘have your say’ section of www.westkentpct.nhs.uk
- posting the feedback form or writing to Personality disorders, Freepost RRJX JYUC UYAC, West Kent PCT, Medway Wharf Road, Tonbridge, TN9 1RE.
- attending one of our discussion groups

What happens next?

You have an opportunity to give your views between 20 April and 27 July 2009.

After the consultation ends, the NHS will think about all the feedback and decide on next steps. A decision will be made towards the end of 2009. Any changes probably won’t happen until 2011 at the earliest.

To decide on next steps, the NHS will weigh up the pros and cons of all the options and any new options that you might put forward during the consultation. The things we will use to weigh up each option include:

- Can the option provide care closer to home / accessible services?
- Can the option meet the needs of a wide range of groups and will it disadvantage any groups?
- Will the option be clinically sustainable? (provide good care long term)
- Will the option be financially sustainable? (able to be funded long term)
- What do people and organisations think of this option?

If you have ideas about any other things we should consider when comparing each option, let us know.

If you have any complaints about the consultation process or documents, you can contact David Griffith, Chair of NHS West Kent, Wharf House, Medway Wharf Road, Tonbridge, Kent TN9 1RE.

The options for future care have been developed by local people and health professionals. Help shape the future by giving your views today.

Discussion groups

9th June 2009 at 2pm in the Boardroom, NHS South East Coast, York House, 18-20 Massetts Road, Horley, Surrey RH6 7DE

12th June 2009 at 2pm in the Derby Room, The Bedford Lodge Hotel, 11 Bury Road Newmarket CB8 7BX

17th June 2009 at 2pm at the Kings Fund, 11 -13 Cavendish Square, London W1G 0AN

19th June 2009 at 2pm at South Central Strategic Health Authority, 1st Floor, Rivergate House, Newbury Business Park, London Road, Newbury, RG14 2PZ

3rd July 2009 at 2pm in the Gascoigne Room, Union Jack Club, Sandell Street, Waterloo London SE1 8UJ

To book your seat for events, get paper copies of extra information, or for any questions contact Shola Oke, ph 01732 375200 ext 5401 or shola.oke@nhs.net
Shaping the future

The NHS wants to know what you think. No stamp is needed to return this form. We need to receive your feedback by 27 July 2009.

1. What do you think of possible ideas for the future?

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<th>Option</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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<td>I agree some changes are needed</td>
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<td>I support the idea of outreach teams</td>
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<td>I support having no live in units</td>
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<td>I support having one live in unit</td>
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<td>I support having two live in units</td>
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<td>Outreach and live in services are needed</td>
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2. Please tell us about any other options for organising care we should think about:

3. Do you think any of the options will be unfair to certain groups, such as women or older people? Please give as many details as you can.

4. What are the most important positive and negative points for each option?

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<thead>
<tr>
<th>Option</th>
<th>Most important advantages</th>
<th>Most important limitations</th>
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<td>No live in units</td>
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<td>One live in unit</td>
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<td>Four live in units</td>
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</table>
5. The NHS will weigh up the pros and cons of each option. Please give each criteria we will use to compare the options a rating from 1 (most important) to 5 (least important).

- Providing care closer to home
- Meeting the needs of a wide range of groups
- Giving clinically effective care long term
- Able to be funded long term
- Fits in with what people say they want

6. Are there any other criteria that the NHS should use to judge or compare each option?

7. Is there anything else you would like to say?

8. Finally a little about you:

- Are you …
  - a (ex) service user or family member
  - a member of the public
  - a healthcare professional
  - a Councillor, MP or other official
  - representing an organisation
  - other – please write here:

- Are you …
  - a woman
  - a man

- What is your age group?
  - under 20 years
  - 20-44 years
  - 45-60 years
  - 61-74 years
  - 75+ years

- What is your ethnic group?
  - White – British
  - White – Irish
  - White – any other White background
  - Asian or Asian British – Indian
  - Asian or Asian British – Pakistani
  - Asian or Asian British – Bangladeshi
  - Asian or Asian British – Any Other
  - Black or Black British – Caribbean
  - Black or Black British – African
  - Black or Black British – Any other
  - Mixed – White and Black Caribbean
  - Mixed – White and Black African
  - Mixed – White and Asian
  - Mixed – Any other mixed background
  - Other ethnic group – Chinese
  - Other ethnic group – Any other group
  - I prefer not to say

- In what area do you live?
  - East of England region
  - London region
  - South Central region
  - South East Coast region
  - Other

Please attach more pages if needed.