The NICE Guideline on Rehabilitation for Adults With Complex Psychosis

Helen Killaspy

Professor and Honorary Consultant in Rehabilitation Psychiatry

University College London and

Camden & Islington NHS Foundation Trust, London

h.killaspy@ucl.ac.uk

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Rehabilitation for Adults With Complex Psychosis; NICE Guideline 181 www.nice.org.uk/guidance/ng181

Aims

- To ensure people have access to mental health rehabilitation when they need it
- To promote a positive approach to long term recovery

Covers

- Organisation and culture of rehabilitation services
- Assessment (including co-morbidities), interventions, care planning

Who is it for?

- Health and social care professionals
- Commissioners of services
- Service users and their families/carers

NICE National Institute for Health and Care Excellence

NICE guideline

Rehabilitation for adults with complex psychosis

NICE guideline
Published: 19 August 2020
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Development of the NICE guideline on mental health rehabilitation

- Lobbying: 2016-2017
- Respond to NICE call for commissioning new guidelines: 2017
- NICE appoint Guideline Committee Chair and Topic Guide through open advertisement: Jan 2018
- Scope drafted: Feb-March 2018
- Public stakeholder consultation on scope: April 2018
- Scope agreed: May 2018
- Guideline Committee appointed through open advertisement: May-June 2018
- 10-12 committee meetings (1-2 days) to agree specification of each evidence review, review evidence, draft recommendations: July 2018-October 2019
- Draft guideline submitted to NICE: December 2019
- Public stakeholder consultation on draft guideline: January to February 2020
- Guideline published: **19th August 2020**

Guideline Committee

Members

- Chair - Gillian Baird
- Topic Advisor - Helen Killaspy
- Psychiatrists - Sri Kalidindi, Jason Read, Tom Craig
- Nurses - Victoria Hulstrom, Helen Bennett
- Psychologist - Jonathan Mitchell
- Occupational Therapist - Melissa Mitchell
- Social worker - Faye Wilson
- Supported accommodation manager - Beth Hendry
- Independent sector manager - Belinda Garnett
- Commissioner - Eugene Reilly
- Service users - Katherine Barrett, James Trevlyan
- Carer - David Shiers
- Pharmacist - James Lee

National Guideline Alliance staff

- Project managers - Eleanor Howat, Bethany Whittaker, Samuel Perwaiz, Joshua South
- Guideline lead - Hilary Eaton, Rachel Marshall, Angela Bennett
- Systematic reviewers - Nathan Bromham, Leanne Saxon, Anuja Pandey, Alec Martin
- Clinical Adviser - Steve Pilling
- Health economists - Matthew Prettyjohns, Ben Purchase
- Information scientists - Agnesa Mehmeti, Sabine Berendse
- Business administrator - Preetpal Doklu

Why NICE Guidelines matter

- Legal status of NICE guidelines is included in the NHS Constitution - patients have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if the doctor responsible for the patient's care says they are clinically appropriate
- Commissioners are accountable for commissioning services that can deliver the treatments and interventions recommended by NICE
  - *Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities..*
- Service providers are responsible for delivering them
  - *When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.*

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In scope

- People with a primary diagnosis of psychosis (schizophrenia, schizoaffective disorder, bipolar affective disorder, psychotic depression, delusional disorder) **plus**
- Severe, treatment refractory symptoms (positive or negative) **plus 1 or more additional;**
  - Cognitive impairment associated with psychosis
  - Co-existing mental health conditions (including substance misuse)
  - Pre-existing neurodevelopmental disorder (e.g. ASD, ADHD)
  - Physical health conditions (e.g. diabetes, cardiovascular disease, pulmonary disease) **plus**
- Impaired social and everyday function (ADLs, interpersonal and occupational)

Out of scope

- Primary diagnosis of common mental disorder (depression without psychosis, anxiety), personality disorder, obsessive compulsive disorder, eating disorder, substance misuse problem, or moderate to severe intellectual disability

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Content of the Guideline

1.1 Who should be offered mental health rehabilitation?
1.2 Overarching principles of mental health rehabilitation
1.3 Organisation of rehabilitation services
1.4 Improving access to rehabilitation services
1.5 Delivering services within the rehabilitation pathway
1.6 Recovery-orientated rehabilitation services
1.7 Person-centred care planning through assessment and formulation
1.8 Rehabilitation programmes and interventions

- activities of daily living (self-care, cooking, cleaning, shopping, budgeting, maintaining a tenancy)
- interpersonal functioning and social skills
- vocational rehabilitation (leisure, education and work)
- healthy living (diet, weight, exercise, sleep, oral health, health monitoring, accessing health services, self-medication programmes, cessation programmes for smoking and substance misuse)

1.9 Adjustments to mental health treatments in rehabilitation
1.10 Physical healthcare

1.1 Who should be offered rehabilitation?

1.1.1 Offer rehabilitation to people with complex psychosis:

- as soon as it is identified that they have treatment resistant symptoms of psychosis and impairments affecting their social and everyday functioning
- wherever they are living, including in inpatient or community settings

In particular, this should include people who:

- have experienced recurrent admissions or extended stays in acute inpatient or other psychiatric units, either locally or out of area
- live in 24-hour staffed accommodation whose placement is breaking down

1.2 Overarching principles of mental health rehabilitation

1.2.1 Rehabilitation services for people with complex psychosis should:

- be embedded in a local comprehensive mental healthcare service
- provide a recovery-orientated approach that has a shared ethos and agreed goals, a sense of hope and optimism, and aims to reduce stigma
- deliver individualised, person-centred care through collaboration and shared decision making with service users and their carers involved
- be offered in the least restrictive environment and aim to help people progress from more intensive support to greater independence through the rehabilitation pathway
- recognise that not everyone returns to the same level of independence they had before their illness and may require supported accommodation (such as residential care, supported housing or floating outreach) in the long term.

1.3 Organising the rehabilitation pathway

1.3.1 All local mental healthcare systems should include a defined rehabilitation pathway

1.3.2 Use the local joint strategic needs assessment to inform the commissioning of specific service components that make up the rehabilitation pathway, to match the needs of the local population.

1.3.3 Conduct a local rehabilitation service needs assessment to identify the number of people with complex psychosis who:

- are currently receiving inpatient rehabilitation ‘out of area’
- have recurrent admissions or extended stays (e.g. > 60 days) in acute inpatient units and psychiatric intensive care units, either locally or out of area
- are currently receiving care from forensic services or early intervention for psychosis services and have or are developing problems that are likely to need mental health rehabilitation
- are young adults moving from children and young people’s mental health services to adult mental health services
- live in highly supported (24-hour staffed) accommodation
- are physically frail and may need specialist supported accommodation

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1.3 Organising the rehabilitation pathway

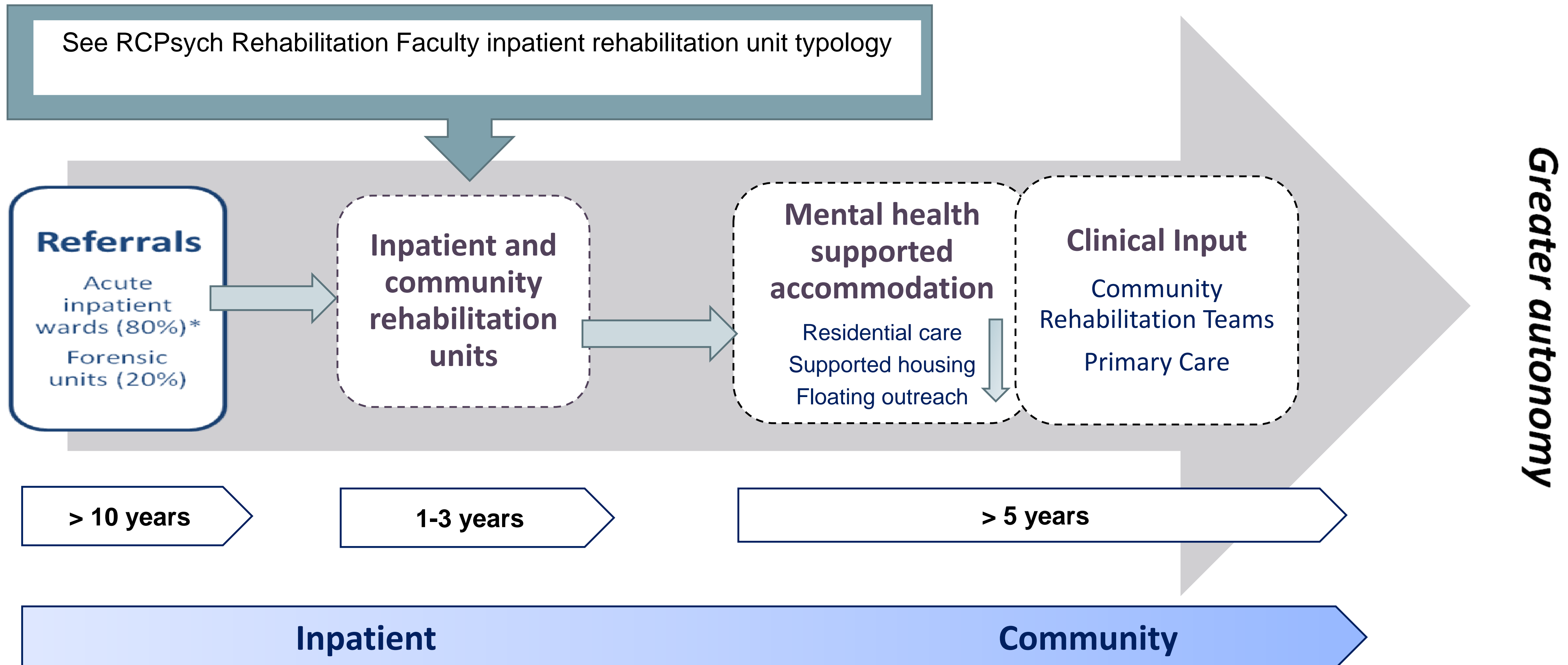
1.3.4 The rehabilitation pathway should include the following components, as informed by the needs assessment:

- rehabilitation in the community, providing clinical care from a community mental health rehabilitation team to people living in supported accommodation (residential care, supported housing and floating outreach) **and**
- rehabilitation in inpatient settings (high-dependency rehabilitation units and/or community rehabilitation units)

1.3.5 Health and social care commissioners should work together with health services, local authorities, housing providers and other partners (third sector and independent sector providers, service users and their families and carers) to ensure that rehabilitation is provided as locally as possible for all those identified in the local rehabilitation service needs assessment.

1.3.6 Consider jointly commissioning the most specialised services (including highly specialist rehabilitation units and longer-term high-dependency rehabilitation units) across areas to provide these services at a regional level for people with particularly complex needs.

The mental health rehabilitation care pathway components



The mental health rehabilitation care pathway

The exact complement of components required will vary between areas as the pathway should be tailored according to the local rehabilitation service needs assessment

1.3.7 The rehabilitation pathway should be designed to provide flexibility, smooth transitions and support over the longer term, that enables people to:

- join and leave the rehabilitation pathway at different points
- move between parts of the pathway that provide higher or lower levels of support according to their changing needs
- spend different periods of time at different stages of the pathway according to need
- have access to more than one period of rehabilitation and be swiftly referred back to the pathway if their needs increase and they would benefit from further rehabilitation.

1.3.8 Health and social care commissioners should jointly designate a lead commissioner to oversee the commissioning of the specific services that make up the defined rehabilitation pathway for people with complex psychosis (see also 1.3.9 to 1.3.14 for specifics on expertise, integration, resourcing, funding structures etc).

1.5 Delivering services within the rehabilitation pathway

1.5.1 Inpatient and community rehabilitation services should be staffed by multidisciplinary teams with relevant skills and competence in mental health rehabilitation:

- rehabilitation psychiatrists
- clinical psychologists
- nurses
- occupational therapists
- social workers
- approved mental health professionals
- support workers (including peer support workers)
- specialist mental health pharmacists

1.5.2 The multidisciplinary team should have access to physical exercise coaches, vocational trainers, welfare rights specialists, dietitians or nutritionists, podiatrists, speech and language therapists and physiotherapists

Community rehabilitation teams

1.5.6 For people with complex psychosis living in supported accommodation, specialist clinical care should be provided by a multidisciplinary community rehabilitation team that:

- holds overall clinical responsibility for their mental health while they are living in the community
- provides a designated care co-ordinator for each person but operate with a shared team caseload approach
- makes the majority of contacts with the person in their home rather than at the team base
- works closely with staff at the person's supported accommodation to tailor people's care plans to their needs and clarifies which staff are responsible for providing specific treatments and support
- supports and oversees the person's progression through the rehabilitation pathway by:
  - increasing the intensity of treatment and support during periods of relapse
  - providing ongoing contact and support during periods of inpatient care and enabling discharge as soon as possible
  - adjusting care plans to enable the person to gain the skills and confidence to manage in more independent accommodation
- liaises with the person's GP about their physical healthcare
- liaises with the relevant service when the person is ready to be discharged from the team to ensure a smooth transition

Out-of-area placements

1.5.13 should be limited to people with particularly complex needs e.g.

- people with psychosis and brain injury, or psychosis and autism spectrum disorder, who need treatment in a highly specialist rehabilitation unit
- people who have a clear clinical or legal requirement to receive treatment outside their home area.

1.5.14 should only be provided after a local placement funding panel (including a rehabilitation practitioner, a senior service manager and local commissioner) has confirmed that the person's care cannot be provided locally.

1.5.15 A designated care manager (or 'out-of-area placement review officer') based within the community mental health rehabilitation team, should review the person's placement after the first 3 months and then every 6 months, to ensure it still meets their needs. This should include:

- reviewing the person's progress with them and the multidisciplinary team at their placement
- agreeing the necessary steps to help the person progress in their recovery so they can transfer to an appropriate placement in their local area at the earliest opportunity (also see the recommendations on maintaining links with the community in the hospital discharge section of the NICE guideline on transition between inpatient mental health settings and community or care home settings).

1.6 Recovery orientated rehabilitation services

1.6.1 Staff in rehabilitation services should aim to foster people's autonomy, help them take an active part in treatment decisions and support self-management.

1.6.2 Staff should build on people's strengths and encourage hope and optimism by:

- helping people choose and work towards personal goals, based on their skills, aspirations and motivations
- developing and maintaining continuity of individual therapeutic relationships wherever possible
- helping them find meaningful occupations (including work, leisure and education) and build support networks using voluntary, health, social care and mainstream resources
- helping people to gain skills to manage both their everyday activities and their mental health, including moving towards self-management of medication
- providing opportunities for sharing experiences with peers
- encouraging positive risk-taking
- developing people's self-esteem and confidence through validating people's achievements and celebrating progress
- recognising that people vary in their experiences and progress at different rates
- improving people's understanding of their experiences and the treatment and support that may help them – for example, through accessible written information, face-to-face discussions and group work

Universal staff competencies

1.6.8 Ensure that staff training emphasises recovery principles so that all rehabilitation staff work with a recovery-orientated approach.

1.6.9 Staff should establish and maintain non-judgemental, collaborative relationships with people with complex psychosis

1.6.10 Provide support for staff to acknowledge and manage any feelings of pessimism about people's potential for recovery. Support could include helping staff to share experiences and frustrations with each other, for example through supervision, reflective practice and peer support groups

1.6.11 Ensure staff attend appropriate diversity training and have the skills and competence to deliver non-discriminatory practice and understand that people may experience stigma resulting from their mental health condition, alongside stigma related to being in a minority group

1.6.12 Ensure that **all staff** are trained and skilled in supporting structured group activities and promoting daily living skills.

1.6.13 Ensure that staff have skills and competence in risk assessment and management to an appropriate level for the service they work in

1.6.14 Ensure that staff are competent to recognise and care for people with psychosis and coexisting substance misuse.

Maintaining and supporting social networks

1.6.15 Discuss with the person whether, and how, they want their family or carers to be involved in their care. Discuss this at regular intervals to take account of any changes in circumstances.

1.6.16 Ensure that staff receive training in the skills needed to negotiate and work with families and carers, and in managing issues related to information sharing and confidentiality.

1.6.17 Respect the rights and needs of carers alongside the person's right to confidentiality. Review the person's consent to share information with families and carers and other services regularly

1.6.18 Give families and carers information about support services in their area that can address their emotional, practical and other needs

1.6.20 Enable the person to maintain links with their home community by:

- supporting them to maintain relationships with family and friends, e.g. by finding ways to help with transport
- helping them to stay in touch with social and recreational contacts
- helping them to keep links with employment, education and their local community activities. This is particularly important if people are in an out-of-area placement.

1.7 Person centred care planning

1.7.1-1.7.3 Offer people a **comprehensive biopsychosocial needs assessment** by a multidisciplinary team within 4 weeks of entering the rehabilitation service.

- developmental history: milestones; relationships with family and peers; problems at school (problems with social or cognitive functioning, motor development and skills or coexisting neurodevelopmental conditions); occupational and educational history
- psychological history: relationships, abuse and trauma, coping strategies, strengths, previous psychological or psychosocial interventions
- social history: accommodation history; culture; ethnicity; and spirituality; leisure activities; finances; current social network including any caring responsibilities; use of substances
- psychiatric history: past admissions and treatments; response to treatments; side effects; adherence
- medicines reconciliation by a specialist mental health pharmacist
- vulnerabilities and risks: self-neglect, exploitation and abuse, risk of harm to self and others
- current skills in activities of daily living
- cognitive impairment and capacity

1.7.4, 1.7.5 Be aware that people with complex psychosis often have comorbid mental health problems

(e.g. anxiety, OCD, ASD, ADHD, BPD, acquired brain injury, cognitive impairment, substance misuse)

Physical health assessment

1.7.3 Offer a physical health check as part of the comprehensive assessment including:

- BMI; waist circumference; pulse and blood pressure; bloods (FBC, U&E, LFTs, HbA1c, lipids, TFTs, prolactin levels, calcium); medication levels (clozapine, mood stabilisers); ECG
- smoking, alcohol and illicit substance use
- nutritional status, diet and level of physical activity
- continence and constipation (particularly if the person is on clozapine)
- movement disorders
- sexual health
- vision, hearing and podiatry
- oral inspection of general dental health
- any difficulties with swallowing

1.7.4, 1.7.6 Be aware that people with complex psychosis often have comorbid physical health problems (e.g. obesity, diabetes, cardiovascular disease, COPD etc)

Care planning

1.7.7 Use the results of the comprehensive assessment to make a team formulation to inform treatment and care planning. The care plan should:

- be developed collaboratively with the person
- include the person's personal recovery goals
- clarify actions and responsibilities for staff, the person themselves and their family or carers

1.7.9 Review people's progress and care plans with them at multidisciplinary care review meetings at least:

- every month in the inpatient rehabilitation service
- every 6 months in the community

1.7.10 Incorporate both staff-rated and service user-rated measurements of the person's progress into their care plan reviews, so that their support can be adjusted if needed.

1.7.11 Update care plans according to changes in the person's needs after these meetings and between meetings as needed. At every meeting or review, consider and plan with the person their transition to the next step in the rehabilitation pathway.

1.7.12 Ensure that care plans are shared with the person and everyone involved in the person's care (clinicians, supported accommodation staff, family and carers, if the person agrees) at each review, each transition point in the rehabilitation pathway and at discharge from the service.

1.8 Rehabilitation programmes and interventions

1.8.1 Develop a culture that promotes activities to improve daily living skills as highly as other interventions

1.8.2 Provide activities to help people with complex psychosis develop and maintain daily living skills such as self-care, laundry, shopping, budgeting, using public transport, cooking and communicating (including using digital technology).

1.8.3 Support people to engage in activities to develop or improve their daily living skills by:

- making a plan with each person that focuses on their needs and regularly reviews their goals
- providing activities they enjoy and that motivate them
- enabling them to practise their skills in risk-managed real life, such as kitchens and laundry rooms, wherever possible

1.8.4 Offer structured group activities (social, leisure or occupational) aimed at improving interpersonal skills. These could be peer-led or peer-supported and should be offered:

- daily in inpatient rehabilitation services
- at least weekly in community settings

1.8.5 Offer regular opportunities to discuss the choice of group activities, for example by inviting everyone in the inpatient unit or supported accommodation service to a 'community meeting'.

1.8.6 Offer regular one-to-one sessions with a named member of staff to help the person plan and review their activity programme (the primary nurse in inpatient rehabilitation or the care coordinator or keyworker in community rehabilitation services).

Community activities

1.8.7 Programmes to engage people in community activities should

- be flexible and make reasonable adjustments to accommodate the person's illness and fluctuating needs
- be individualised
- develop structure and purpose in the person's day
- aim to increase their sense of identity, belonging and social inclusion in the community
- involve peer support
- recognise people’s skills and strengths

1.8.9 Offer people a range of educational and skill development opportunities, for example, recovery colleges and mainstream adult education settings, which build confidence and lead to qualifications if the person wishes

1.8.10 For people who would like to work towards mainstream employment, consider referring them to supported employment that uses the Individual Placement and Support approach

1.8.11 Take into account and advise people about the impact of supported employment on their welfare benefits.

1.8.12 For people who are not ready to return to paid employment, consider alternatives such as transitional employment schemes and volunteering

1.8.13 Consider providing a cognitive remediation intervention alongside vocational rehabilitation services.

1.8.14 Develop partnerships, for example with voluntary organisations and local employment advice schemes, to increase opportunities for support to prepare people for work or education

1.9 Adjustments to mental health treatments in rehabilitation

1.9.1 First - follow relevant NICE guideline (schizophrenia, bipolar affective disorder etc)

1.9.7 Consider additional psychological interventions, especially for people who are not ready to engage in CBT e.g. mindfulness, therapeutically informed environments.

1.9.8 Consider training all rehabilitation staff in motivational interviewing, positive behaviour support, behavioural activation, trauma-informed care.

1.9.9 For people with complex psychosis whose symptoms have not responded adequately to an optimised dose of clozapine alone, consider augmenting clozapine with the following, depending on target symptoms:

- an antipsychotic, for example aripiprazole for schizophrenia and related psychoses and/or
- a mood stabiliser for psychosis with significant affective symptoms and/or
- an antidepressant if there are significant depressive symptoms in addition to the psychotic condition

Be aware of potential drug interactions and note that not all combinations of treatments may be in accordance with UK marketing authorisations. Any off-licence prescribing should be communicated in writing with the person's GP. Seek specialist advice if needed, for example from another psychiatrist specialising in treatment-resistant symptoms or a specialist mental health pharmacist. Do not offer valproate to women of childbearing potential, unless other options are unsuitable and the pregnancy prevention programme is in place. Follow the MHRA safety advice on valproate use by women and girls.

Medication management

1.9.10 Optimise the dosage (as tolerated) of medicines used to manage complex psychosis according to the BNF and therapeutic plasma levels in the first instance

1.9.11 Only use multiple medicines, or doses above BNF or summary of product characteristics limits, to treat complex psychosis:

- if this is agreed and documented by the multidisciplinary team and the person (and their family, carer or advocate, as appropriate)
- as a limited therapeutic trial, returning to conventional dosages or monotherapy after 3 months, unless the clinical benefits of higher doses or combined therapy clearly outweigh the risks
- if the medicines are being used to treat specific symptoms that are disabling or distressing
- after taking into account drug interactions and side effects
- if systems and processes are in place for monitoring the person's response to treatment and side effects (monitoring may include physical examination, ECG and appropriate haematological tests)

Medication management

1.9.12 Regularly review medicines used to manage complex psychosis and monitor effectiveness, adverse effects (including constipation for those taking clozapine) and drug interactions

1.9.13 If pharmacological treatment is not effective, **consider stopping** the medicine:

- following a thorough review of treatment
- after agreeing and documenting the decision at a meeting with a multidisciplinary team and the person (and their family, carer or advocate, as appropriate)
- with caution, particularly if the person has been on the medicine for many years
- by reducing the dose slowly and closely monitoring the person for symptoms of relapse

1.9.14 Monitor drug levels to check adherence and guide dosing

- At least annually and as needed for clozapine and mood stabilising anti-epileptic medicines (be aware that changes in smoking affect clozapine levels)
- Every 3 to 6 months for people established on lithium

1.9.15 – 1.9.18 – monitoring prolactin, thyroid, ECGs and changes in smoking

1.10 Physical healthcare

1.10.1 GPs should develop and use practice case registers to monitor the physical and mental health of people with complex psychosis in primary care

1.10.2 For people having community rehabilitation, GPs should assume lead responsibility for the person's physical health needs, including health checks and treatment of physical health conditions, working collaboratively with the community mental health rehabilitation team and other services as relevant

1.10.3 For people having inpatient rehabilitation, the rehabilitation team should ensure that health checks, treatment of physical health conditions and other healthcare needs are addressed

1.10.4 Nominate a professional from the rehabilitation service to provide continuity of physical healthcare across settings, liaising between the rehabilitation service, primary care, secondary mental health and secondary physical healthcare

1.10.5 The nominated professional should work in collaboration with a healthcare professional to develop and oversee the physical healthcare plan – this should address any physical health care problems, health promotion, screening, routine monitoring of physical health and medication side effects, and clarify which practitioners are responsible

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Use it or lose it!

Many thanks
for your attention

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