Care & Treatment Reviews

A Family Survival Guide

Created by families

Introduction

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Welcome to our family survival guide to Care and Treatment Reviews (CTRs). This guide has been written to help families understand and cope with the CTR process.

The guide not only focusses on the period before, during and after a CTR, but also covers related topics to help you understand the complicated process. It is based on NHS England guidance, as updated in March 2017, and has been developed with the help of some very dedicated parents with a wealth of lived experience.

Urgent help

If you are worried about the immediate safety of your loved one and they are at risk of hurting themselves or others around them, enact your crisis plan if they are living with you. You can find our Crisis Planning Guide and Template _here_.

If care is being provided by someone else, contact a senior care manager urgently and inform them of your concerns.

If someone is at risk of harm from abuse, neglect or exploitation, contact your local safeguarding team without delay.

How to use this guide

The information has been arranged to support families at any stage in the CTR process. It begins at the point before a crisis has developed, takes you through assessment and treatment, and ends with discharge and beyond.

Tools and references have been included so that you can dip in and out as required. Links to further resources at the end will help you carry out further research as needed.

If you find it helpful, please tell your friends and colleagues. All feedback, good or bad, is very welcome. Contact us at: Debs@bringingustogether.org.uk

NB: Throughout this guide, we will refer to a Care & Treatment Review as a CTR and a Care & Education Review as a CETR. For this guide's purpose, the information about CTRs will also apply to CETRs unless otherwise stated.

All About CTRs

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What is a CTR?

A CTR is a meeting to check that a person's care and treatment is meeting their needs.

A CTR may be held for anyone with learning disabilities, autism or both who may be at risk of admission to, or who is already in, a specialist learning disability or mental health hospital.

There are now two versions of the Care and Treatment Review. One is for adults and is still known as a Care and Treatment Review (CTR). The other is for children and young people and is called a Care, Education and Treatment Review (CETR). Each has its own code and toolkit.

The following people may be invited to attend reviews:

- The person;
- Their advocate if one has been appointed;
- A family member[1]; and
- Those responsible for providing the individual's care.

The review is led by the responsible commissioner with support from two independent expert advisers whose role is to bring an additional challenge and an alternative perspective. The review team makes recommendations to improve the individual's care with follow-up checks to ensure this is happening. A CTR may last a full working day (for example take place between 9am and 5pm).

When is a CTR held?

A CTR can be held before or during care in one of four ways:

Community Pre-admission. This review seeks to establish whether the person needs to be admitted to hospital, or whether their care and treatment needs could be met safely and effectively in the community instead.

Local Area Emergency Protocol. This is used when a review is unplanned, urgent or if someone is in 'crisis'. Its duration is variable and it can be via face-to-face meeting or secure teleconference.

Post-admission. This takes place within four weeks of admission unless it is for a child when the meeting is held within two weeks of admission.

Inpatient. These reviews should be held at regular intervals to identify the reasons for an extended hospital stay and any barriers to progression and discharge. The meeting should include a review to find out whether the correct and most effective treatment is being provided.

How often can you have a CTR?

For children and young people, a CETR should take place every three months.

For adults, a CTR should take place every six months if the person is in an assessment and treatment unit or another type of non-secure hospital.

If the person is in a secure hospital the CTR should take place every twelve months.

If there are good reasons for having a CTR more often, everyone involved can agree when they should happen.

You also have the right to request a CTR at any time. There is more about this here.

What happens in a CTR?

Before the meeting takes place, the commissioner/chairperson will make sure that the appropriate consent has been obtained from the person under review. If the person does not have capacity to give consent, a best interests decision to continue the review should be made under the Mental Capacity Act.

On the day of the CTR meeting, the first task will be for the chairperson to finalise the agenda so that everyone invited will have an opportunity to take part in person. Some people may join in via teleconference if they are unable to travel to the meeting.

Before anyone else joins the meeting, the review team will study the patient's clinical and support documentation to learn as much about them and their care programme as possible.

Early on in the process, one or both of the independent experts will wish to meet the person and their parent, guardian or other

unpaid carer if available. It is very important to hear their views about the care and treatment being provided and to make sure that their voices are heard during the review. The person, their advocate (if one has been appointed) and a family member[1] also have the right to join the meeting.

The chairperson will then invite one or more of the professionals involved in providing or managing the care programme into the meeting room, together or in succession, to provide a summary of care and to answer questions from the panel.

The review team will seek to answer the following questions:

* Is the person safe?

* Are they getting good care now?

* What are their care plans for the future?

* Can care and treatment be provided in the community?

Under each of these four main headings is a list of other important questions known as Key Lines of Enquiry (KLOE) which help guide and structure the review process.

Once all attendees have been interviewed, the chairperson and the independent experts will discuss what they have heard and together write up a detailed report based on a standard CTR template.

Each KLOE section of the report contains a list of prompt questions about the quality of care being provided. Notes, comments and concerns are entered alongside each question and a red, amber, or green (RAG) score given for each section. Any actions raised should state a named individual responsible for the action and the expected completion date of that action. Use of the standard template makes sure that the final report is consistent, to a high standard and that all actions are completed in a timely manner.

Finally, the chairperson may provide a verbal summary of the CTR outcomes to senior hospital staff before concluding the meeting. The person and their family should also be offered verbal feedback at the end of the CTR.

The final report will be sent by the chairperson to the person, their advocate (if one has been appointed), a family member[1] and the care team within two weeks of the CTR.

If you have any questions arising from the report, you should contact either the care manager or the commissioner responsible.

(1) if the patient is 16 or older consent is required

Who does What?

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The chairperson (commissioner) is responsible for the package of care, making sure it meets the assessed needs of the patient through care and treatment. The chairperson works with others to identify local arrangements to support the individual to remain in, or move back to, their local community as soon as possible with appropriate support.

The two independent experts use their clinical and lived experience to make sure that the voice of the patient is heard. They ensure all of the four main questions and KLOE are covered at the meeting, providing challenge along the way if necessary.

Depending on the needs of the individual, a combination of the people listed in the table below may attend the CTR in person or remotely by teleconference.

Role	Function
Chairperson	Responsible Commissioner
Independent Clinical Expert	Clinical experience reviewer
Independent Expert by Experience	Lived experience reviewer
The individual	Person whose care is being reviewed
Family Member	Family representative[1]
Advocate	Individual's advocate *(if appointed)*
Care Manager	Professional responsible for the Care Plan
Responsible Clinician (RC)	Psychiatrist responsible for care & treatment
Clinical Psychologist	Psychologist who aims to reduce the distress and improve the psychological wellbeing of their clients. May use behaviour management or therapies.
Forensic Psychologist	A psychologist who specialises in the assessment and treatment of offending behaviour. Provides psychological assessment, support and treatment plans for those patients who have come into contact with, or are at risk of, coming into contact with the criminal justice system.
Care Programme Approach Care Coordinator	Professional responsible for CPA planning, care and support.
Social Worker	Social care case manager
Education Coordinator (Local Authority)	EHCP/education lead
CMHT Lead Professional	Community LD/MH team nurse
Community Nurse	LD/MH team lead (Community CTR)
Community Care Provider	Community placement lead professional
Occupational Therapist (OT)	Therapist providing functional assessments and support plans for the development of practical skills.
Speech and Language Therapist (SaLT)	Therapist providing assessment and support for communication problems, or for difficulties with eating, drinking or swallowing.
Community Care Service Provider	Professional responsible for providing community living and support on discharge

(1) if the patient is 16 or older consent is required

What makes a good CTR?

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The updated policy and guidance published in March 2017 brings lots of changes designed to improve the effectiveness of CTRs. It introduces a clear commitment to autism and includes a new Policy Annex on CETRs.

The new guidance builds on the existing four key questions:

Key CTR questions

* Is the person safe?

* Are they getting good care now?

* What are their care plans for the future?

* Can care and treatment be provided in the community?

The new KLOE sets (*outlined on pages 11 and 12)* are supported by a new acronym, PERSONAL, which explains the principles of a good CTR.

PERSONAL stands for:

Person-centred and family-centred

Evidence-based

Rights-led

Seeing the whole person

Open, independent and challenging

Nothing about us without us

Action-focused

Living life in the community

SMART outcomes

To make the CTR activity more accountable and effective, the CTR frameworks will expect that recommendations will be made in the context of SMART outcomes:

Specific	What exactly should happen and the name of the person responsible for ensuring that it is carried out?
Measurable	How will people know if the recommendation has been implemented satisfactorily?
Action-focused	Recommendations should be in the form of clear tasks to be carried out by named persons.
Realistic	Recommendations have to be possible to achieve and not merely aspirational or outside the remit or capabilities of the individuals named.
Time-framed	There should be a specific stated date by which the recommendation is to have been implemented or reviewed.

My CTR

Two brilliant new booklets will help your loved ones understand and organise their CTR. These are:

- *My Care and Treatment Review: All you need to know about your CTR*; and

- *My CTR Planner* (Includes consent form, planner, report and feedback forms).

These are well worth using. Both can be downloaded from this page: *https://www.england.nhs.uk/learning-disabilities/ctr/my-ctr/*

Key lines of enquiry

The Key Lines of Enquiry (KLOE) for CTRs and CETRs are slightly different to reflect the differing needs of Adults (CTR) and children and young people (CETR). The CETR, being specifically aimed at children and young people, includes a greater emphasis on the need for engagement by local authorities and education services:

11 KLOEs for an adult CTR:

1. Key areas of concern.

2. Does the person need to be in hospital?

3. Is the person receiving the right care and treatment?

4. Is care person-centred?

5. Are the person's health needs known and met?

6. Is there the right use of medication?

7. Are there clear, safe and positive approaches to risk?

8. Are any autism needs being met?

9. Is there active planning for the future and discharge?

10. Are families and/or carers involved?

11. Are the person's rights upheld?

12 KLOEs for a child or young person CETR:

1. Key areas of concern.

2. Does the child or young person need to be in hospital?

3. Is the child or young person receiving the right care, education and treatment?

4. Is the child or young person being involved in their care, education and treatment?

5. Are the child or young person's health needs known and met?

6. Is there the right use of medication?

7. Are there clear, safe and positive approaches to risk?

8. Are any autism needs being met?

9. Is there active planning for the future, including discharge from hospital?

10. Are parent(s) / carers, family members and other carers involved?

11. Are any specific issues for children or young people being addressed?

12. Are the child or young person's rights being upheld?

The panel should look for proof or evidence of the care being delivered. This might be forthcoming from the person's care notes or from what people say. The chairperson needs to show how or why the panel decides on something.

CTR document checklist

Before attending the CTR meeting, the independent experts are unlikely to know anything about the person, their background or the care being provided. They will, therefore, expect an information pack to be prepared and shared at the start of the meeting to enable them to learn about the person quickly and comprehensively.

These are the documents that should be prepared for the CTR panel and put into a pack. The CTR panel will not take any of these documents away with them nor will they make copies of them to take away. The CTR chairperson

will be responsible for ensuring that all written and verbal information provided will be kept private and confidential within the CTR.

For a CTR in a hospital, the responsibility for producing the pack is with the provider.

For a community CTR, the commissioner is responsible.

CTR Documents will typically include:

- Risk assessments;

- Mental Health Act papers;

- The most recent Mental Health Act Tribunal report;

- Social circumstances report;

- The community service specification;

- The last four weeks of progress notes;

- Safeguarding reports from the last year;

- Incident forms where restraint was used, either since admission or last CTR;

- Health Action Plan;

- Person-Centred Care Plan;

- Positive Behaviour Support Plan and other care plans;

- Communication Passport;

- Hospital Passport;

- Medication Chart;

- Mental Capacity Assessments;

- Ministry of Justice documents, where appropriate;

- Activity Planner; and

- Discharge Plan (if in hospital).

For a CETR, the local authority can provide:

- Child in Need Plan;

- Child in Care or Looked After Child Plan;

- Other relevant education or social care assessments or plans (e.g. EHCP); and

- Any relevant youth justice assessment or plan.

Further information
CTR document checklists can be found on page 33 on the link below:
https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-code-toolkit.pdf

CETR document checklists can be found on page 38 on the link below:
https://www.england.nhs.uk/wp-content/uploads/2017/03/children-young-people-cetr-code-toolkit.pdf

Treatment Pathway / Tools

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NHS England Care and Treatment Reviews Homepage - Here you will find all the current information and resources for CTRs from NHS England: *https://www.england.nhs.uk/learning-disabilities/ctr/*

CTR and CETR Pathways - For policy and guidance, including policy and guidance on CETRs for children and young people, go to*: https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf*

Person-Centred Plans

Good planning supported by comprehensive information is vital in order to provide high quality support in any setting. The following list is an example of the person-centred documents that should be available and up to date:

- Person-Centred Care Plan;

- Positive Behaviour Support Plan and other Care Plans;

- Risk assessments;

- Communication Passport;

- Hospital Passport;

- Health Action Plan;

- Mental Capacity Assessment;

- Ministry of Justice documents (where appropriate);

- Activity Planner;

- Discharge Plan (if in hospital); and

- Education Health & Care Plans or SEN Support Plans.

Positive Behaviour Support

Positive Behaviour Support (PBS) is a structured approach to supporting people when there are challenging behaviours. It moves the focus away from what is challenging to supporting positive behaviours. Challenging behaviours are assessed to identify what they mean for the person and then support is given to develop alternative skills to meet this purpose[2].

(2) PBS4 factsheet: http://pbs4.org.uk/?media_dl=514

A Behaviour Support Plan is created to help understand and manage behaviour in children and adults who have learning disabilities and display behaviour that others find challenging.

What is a Behaviour Support Plan?

A Behaviour Support Plan provides carers with a step-by-step guide to ensuring that the person has a great quality of life. It also enables carers to identify when they need to intervene to prevent an episode of challenging behaviour.

A good Behaviour Support Plan is based on the results of a functional assessment and uses PBS approaches. The plan contains a range of strategies which not only focus on the challenging behaviour(s), but also identify ways to ensure that the person has access to things that are important to them. The strategies used are referred to as Proactive Strategies and Reactive Strategies.

Proactive strategies are intended to make sure the person has the things they need and want on a day-to-day basis, and also includes ways to teach the person appropriate communication and life skills.

Reactive strategies are designed to keep the person and those around them safe from harm. They provide a way to react quickly in a situation where the person is distressed or anxious, and more likely to display challenging behaviour.

A good Behaviour Support Plan has more proactive strategies than reactive ones. This helps to ensure that the focus of the plan is not just on the challenging behaviour, but also provides ways to support the person to have a good life. The person will be enabled to learn better, more effective ways of getting what they need.

Further Information

Information Sheet: *Positive Behaviour Support Planning: Part 3*
http://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf

PBS4: Resources factsheets
http://pbs4.org.uk/resources-factsheets/

Helen Sanderson Associates: Person-centred Practices*: http://helensandersonassociates.co.uk/person-centred-practice/*

Medication (including STOMP)

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Psychiatry is a medical specialty concerned with the diagnosis, treatment and prevention of mental health conditions. Psychiatrists use a range of psychological treatments in their work, including medication.

During assessment and treatment, Psychiatrists will sometimes prescribe powerful drugs as a part of a patient's treatment plan, and of course have a responsibility to use medication safely and appropriately. While medication may be an essential part of treating severe mental illness, there have been concerns that powerful medicines are sometimes being used excessively, and in some cases inappropriately: for example, as a 'chemical restraint' to control challenging behaviour, in place of other more appropriate treatment options; or for the management of core symptoms of autism.

During the CTR, information will be sought by panel members on specific diagnoses and formulations, including physical health care problems, the use of medication and any restrictive practices. The panel will ask to see the patient's medication chart, will explore and gather information to confirm the right use of medication (KLOE 6), and to confirm that full and regular reviews of medication are taking place. In doing so, they aim to make sure the patient is not taking medicines that they don't need and to find other ways of helping them. This will all go some way towards confirming KLOE3: 'Is the person receiving the right care and treatment?'.

As some of the drugs used can potentially cause side effects (for example, weight gain, diabetes and constipation), the Panel will check if these have been considered, assessed and managed appropriately.

As you will see on the following page, the issue of the inappropriate use of psychotropic medication has become a significant issue, which is now being addressed by NHS England and its partners.

Introducing STOMP

The acronym STOMP stands for:

Stopping the **O**ver-**M**edication of **P**eople with a Learning Disability, Autism or Both.

STOMP is a health campaign to stop the over-use of psychotropic medication particularly to manage and control patients who exhibit challenging behaviour.

Research carried out in 2015 concluded that there was widespread inappropriate use of antipsychotic and other medications in treating mental illness in people with learning disabilities. As a result, a National campaign and Toolkit targeted at clinicians in hospitals and general practice is trying to address this.

A key aim of STOMP is to ensure that clinicians only offer antipsychotic medication in combination with psychological or other interventions including positive behaviour support.

A pledge, guidance, and a self-assessment and action planning template for social care has also been launched (April 2017) to further embed the philosophy.

There is little doubt that experienced clinicians have very difficult choices to make where the causes of sometimes profound and traumatic symptoms may not be clear. However, we all hope that in time the STOMP will help us ensure that powerful drugs are the last tool out of the box, not the first.

Further Information

Medicine advice for patients
https://www.england.nhs.uk/learning-disabilities/STOMP/

Stopping the Over-Medication of People with a Learning Disability, Autism or Both
https://www.cppe.ac.uk/wizard/files/publications/leaflets/stopping%20over-medication%20of%20people%20with%20a%20learning%20disabilitiy,%20autism%20or%20both%20nhs%20leaflet.pdf

STOMP Campaign from VODG
https://www.vodg.org.uk/campaigns/stompcampaign/

STOMP it out! (Easy Read)
https://www.cppe.ac.uk/wizard/files/publications/leaflets/stomp%20it%20out%20nhs%20leaflet.pdf

STOMP Guidance for Social Care
https://www.vodg.org.uk/wp-content/uploads/2906234-STOMP-Guidance-for-Social-Care-DP-ACCESSIBLE-10703-v1_1.pdf

STOMP Best Practice Guide, (Care Management Group)
http://cmg.co.uk/wp-content/uploads/2017/06/STOMP-Guide-Final-version.pdf

Psychotropic Medication Review example form - format may vary
https://www.england.nhs.uk/wp-content/uploads/2017/03/medication-review-form.docx

Coping with the medication enigma

Medication is a very difficult subject for us parents, and our loved ones, to understand and cope with. This may be for various reasons including the medical complexities of mental health treatment, the sometimes profound effect that powerful medication can have on our loved ones (and us) and the statutory power of clinicians over their patients.

No doubt that the presence of a learning disability and/or autism significantly complicates assessment and treatment. Particularly when challenging behaviour is involved, doubts (based on our lived experience) may arise in our minds that using powerful medication may not be the most appropriate way to treat presenting behaviours that could be the result of a number of triggers other than a mental health illness.

An ongoing crisis may require urgent temporary psychotropic intervention to help with initial recovery. However, it is important that continuing assessment and treatment addresses the causes of the behaviour and not just the symptoms.

It can be difficult for families to work with care staff, psychiatrists and others. Busy teams have their focus (hopefully) on their patients and communication with families is sometimes not seen as a priority. However, the relationship between us and the professionals is very important, and needs to be nurtured. Here are some tips:

- The lead Nurse or care coordinator is your main contact and source of information, who can also help liaise with the wider care team and share information with consent. Maintaining goodwill is very important.
- Each hospital and ward will have their own ways of managing the day-to-day routine, so adapt accordingly for best effect and minimum distraction.
- Try not to cross-examine or be openly critical of treatment. You have so much lived experience to share, tell them that you want to help as an equal partner.
- If you feel that the needs of your loved one are not been addressed effectively or taken seriously, talk to the care coordinator, stating your concerns clearly and respectfully.
- If you have concerns, try to deal with these informally. Keep copies of all correspondence and keep you diary record up to date.
- Each hospital or Clinical Commissioning Group will have a complaints policy. If you need to make a formal complaint, try to keep it brief and specific, copying in the care commissioner.

During the CTR, the independent clinical expert will lead on medication questions. S/he will ask to see the medication chart, the treatment plan and check evidence of appropriate medication reviews. S/he will also check what steps are being taken to minimise any psychotropic medication. This will all help confirm the right use of medication (KLOE 6) or otherwise.

Both experts are there to help make sure that care of a high standard is being delivered and an important part of their role is to challenge the professionals positively when necessary.

The chair is expected to make sure that the CTR is Person-centred and family-centred, and that everyone is treated with respect and given the right amount of time to take part.

A checklist for carers of people with mental health problems
http://www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/ checklistforcarers.aspx

Accessible Information about Medication

How medicines to treat mental health problems are used for people with learning disabilities
https://www.england.nhs.uk/wp-content/uploads/2015/07/ld-med-advice-letter-easy-read.pdf

Advice for patients, families and carers
https://www.england.nhs.uk/wp-content/uploads/2015/07/ld-med-advice-easy-read.pdf

Easy-read Health Leaflets
http://www.easyhealth.org.uk/categories/health-leaflets/

Medication Reviews

Royal College of Psychiatrists - Antipsychotics
http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/ antipsychoticmedication.aspx

Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines (RC Psych)
https://www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf

Psychiatric drugs: an alphabetical list
https://www.mind.org.uk/information-support/drugs-and-treatments/ medication-drugs-a-z/#.WUrCzYWcF9C

What do I need to know about side effects?
http://www.mind.org.uk/information-support/drugs-and-treatments/
medication/coping-with-side-effects/#.WPtqlIWcF9A

Patient involvement

Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence.
https://www.nice.org.uk/guidance/cg76/chapter/1-Guidance

Discharge standards

Section 10 of the updated CTR/CETR Code provides a detailed list of discharge steps and standards to help everyone plan the discharge process.
https://www.england.nhs.uk/publication/care-and-treatment-review-code-and-toolkit/

With regard to medication, Standard 7 says:

'While I am in hospital and before I am discharged, I will have full and regular reviews of my medication to make sure I am not taking medicines that I don't need and to find other ways of helping me"

Page 18 https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review-symbol.pdf

This will be measured by:

'Medication reviews will be shown on my discharge documents, letters to or from my GP, responsible clinician and community team"

The same Standard can be found on page 18 in the *My Care and Treatment* booklet which is a guide to CTRs that all patients should be given -
https://www.england.nhs.uk/publication/my-care-and-treatment-review/

Physical Health considerations and health record

Physical Health considerations and health record

Maintaining physical health is vital and the CTR panel are required to ask a number of questions and see evidence that there are appropriate checks and procedures in place to make sure that the person is safe and that the Care being provided is meeting their needs. This will be confirmed or otherwise by direct questioning about on-going health care and a review of documentation including a health action plan, Communication and Hospital passports, assessments and reports. (Key CTR questions: 'is the person safe' and 'Are they getting good care now' plus KLOE 3, 5 and Standard 4.4 refers).

Further Information

Providing links to resources for supporting the physical health of people with mental health problems and learning difficulties, and the mental health of people with physical health problems.
http://www.rcpsych.ac.uk/mentalhealthinfo/improvingphysicalandmh.aspx

My physical health A physical health check for people using mental health services.
https://www.rcpsych.ac.uk/pdf/RethinkPHchecklist.pdf

Physical health resources
https://www.rethink.org/about-us/health-professionals/physical-health-resources

The Use of Medication (Challenging Behaviour Foundation)
http://www.challengingbehaviour.org.uk/understanding-behaviour/use-of-medication-sheet.html

Managing medicines for adults receiving social care in the community NICE guideline [NG67]
https://www.nice.org.uk/guidance/ng67

Learning Disabilities Hub
https://www.cppe.ac.uk/services/ldhub

Crisis Planning

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Some people use a Wellness Recovery Action Plan (WRAP) to help manage their mental health on a daily basis. The WRAP plan identifies activities that help people feel better (known as 'wellness tools') and support networks to help promote confidence, resourcefulness and self-management. The plan also identifies the triggers that can lead to mental ill health and to the possibility of a crisis situation developing. It is vital that we try to avoid a crisis situation as this often leads to an admission to hospital.

NICE Quality standard [QS14/9] states that a crisis plan should contain:

- Possible early warning signs of a crisis and coping strategies;

- Support available to help prevent hospitalisation;

- Where the person would like to be admitted in the event of hospitalisation;

- The practical needs of the person if they are admitted to hospital (for example, childcare or the care of other dependants, including pets);

- Details of advance statements and advance decisions;

- Whether, and the degree to which, families or carers are involved;

- Information about 24-hour access to services; and

- Named contacts.

Each person is different so any plan will be unique. There are, however, templates available that help identify all the important topics but leave space for personal content to be entered to suit the needs of each individual.

Crisis Planning Templates

You can find our Crisis Planning Guide and template *here*

Further Resources

Wellness Recovery Action Plan from [Recovery Devon] Contains a daily maintenance plan, crisis plan and post crisis plan, this template is designed for those able to play a significant role in creating and managing their own plan: *https://recoverydevon.co.uk/wp-content/uploads/2010/07/WRAP_Book_A4.pdf*

LD WRAP Book and easy read template from Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH).

- *LD WRAP Planning Book*
  http://www.rdash.nhs.uk/wp-content/uploads/2014/04/LD-WRAP-Book-April-13.pdf

- *LD WRAP2*
  http://www.rdash.nhs.uk/wp-content/uploads/2014/04/LD-WRAP-2b-April-13.pdf

WRAP template from Surrey and Borders Partnership NHS Foundation Trust *http://www.sabp.nhs.uk/recovery/moving-forward/professionals/wrap-template*

Mental Health Easy Read (leaflets) from Easy Health
http://www.easyhealth.org.uk/listing/mental-health-(leaflets)

Requesting a CTR

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The request for a CTR can be made by the following people[1]:

- The individual in receipt of services;

- The individual's family or carer;

- The Responsible Commissioner;

- The advocate for the individual in receipt of services; and

- The team who are supporting the individual, either from inpatient services

The CTR can be requested at any point along the inpatient pathway when there are concerns regarding the suitability of the service and/or of the treatment plan, the individual's safety and wellbeing, and/or if there is no clear discharge or transfer date and plan.

Requests for CTRs should be directed to the CPA care coordinator. His or her first response should be to address the concerns that have led to the request as promptly and thoroughly as possible, potentially mediating any concerns or dissatisfactions without the need for a review. Should the applicant continue to feel that a CTR is necessary, then the care coordinator will contact the commissioner who will process this request according to locally established protocols and respond to the request for a CTR.

NB: The CTR request should not be regarded in itself as a form of complaint and should not be handled through usual complaints channels.

Further information

For more details on how to request a CTR , please see the flow chart on page 38 of the *Care and Treatment Reviews (CTRs): Policy and Guidance.* Similarly the pathway for Care, Education and Treatment Review on request can be found on page 54, both available on the link below*:*
https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf

For easy-read version of this guidance, please see page 13 of *My Care and Treatment Review*, available on the link below: *https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review.pdf*

(1) if the patient is 16 or older consent is required

Preparing for the CTR

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Arrangements for a CTR should begin at least two weeks before the meeting. The person whose care and treatment is to be reviewed will be given information about the process and a _My Care and Treatment Review_ booklet. They will be asked to consent to the review taking place and to say whom they would like to be involved.

If the person consents to the review taking place, another booklet called _My CTR Planner_ will help them prepare and plan for the review and what happens next. It also has a consent form to fill in. The planner can either be filled in on a computer, or printed off and filled in by hand.

Appropriate support should be provided to help the person fill in all the suggested information in the planner. This will not only confirm their consent but will also help them record their views which can be shared and heard at the meeting.

If the person lacks capacity to make a decision about the review, a best interests decision will be made on their behalf. If an independent advocate is required, this will be arranged at the same time and appropriate support provided.

You (the family member concerned[1]) will also be contacted by the commissioner (or their representative) at least two weeks before the CTR. The commissioner will ask if you would like to be involved and, if so, whether you would like to attend in person, or remotely by telephone or video conference. You will be sent information explaining the CTR process with details of the names and roles of those on the review panel. If a best interests decision has been made, the family member should ask who carried it out and how. Family members should respond to the invitation as soon as possible. If you will only be available for part of the day, make this clear. If you have additional needs or need help to attend, let them know.

If you are unable to attend, ask the inviter if it will be possible to rearrange the CTR to help you fit it in with your other commitments.

(1) if the patient is 16 or older consent is required

Tips to help you prepare:

- If you need help to speak up, contact _Bringing Us Together_ for some support;

- Make/check travel arrangements;

- In the days before the review, use a small notebook to make two lists of questions:

     - one list for your conversation with the independent member of the panel;

     - a second list for anything you may want to ask at the meeting itself;

- Try not to worry about the review because it is a process to help you have your say;

- Consider drawing up a list of contacts using the template provided;

- Prepare a list of current medications, their action plus any side effects;

- If you have notes from the previous CTR, get them ready to take with you;

- Read this _Survival Guide_ if you have time to find out more about related topics;

If you have time to find out more about related topics:

- Read _My Care and Treament Review_ booklet, it's full of helpful information;

- Consider using some _Person-Centred Thinking Tools_ to aid decision making; and

- There is a blank contact sheet on page 46 of this guide which you can use to note important contacts.

Further information

For more information on preparing for the CTR, please see page 23 of _Care and Treatment Reviews (CTRs): Policy and Guidance_ available on the link below:
https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf

Surviving the CTR

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This may feel like a very stressful time, but try to stay calm. This is not an adversarial process; everyone tries to work together to meet the needs of the person concerned.

If you take part in the meeting, expect to hear a range of opinions and views expressed. You have a right to share your views based on your personal experience, as does your loved one who will be offered their own support to help them have their say.

Community CTR

If this is a community CTR, the aim will be to stop things breaking down and avoid an admission to hospital. Everyone will be trying to stop this happening. The review will make sure that a detailed assessment is carried out and the right community support established as soon as possible to meet the needs of the person.

Inpatient CTR

If this is an inpatient CTR review, it is an important opportunity to evaluate the care being provided to make sure that appropriate steps are taken to treat your loved one effectively and to discharge them as soon as they are well enough to move back into the community.

Remember that two of the three core panel members at a CTR are independent of the care being provided. They will be able to provide an objective view and challenge the professionals when necessary.

When you arrive, you will probably need to sign in. Depending on the security arrangements in place, you might also be asked to put your purse, wallet, phone or other personal things in a secure locker. This is so they are kept safe while you are there.

You will then be escorted to a waiting room while the panel get ready. The review starts with a meeting of the panel members to talk about the day, fix meeting times, find out more and ask for notes. As a result, there may be a wait before anything happens.

As soon as the panel is ready, someone will come and meet you. Before you join the main meeting, you may be asked if you would like to speak to the independent member of the panel who, like you, has lived experience. This panel member is known as an Expert by Experience (E by E).

Speaking with the E by E is a really good opportunity to share your views and experiences. It will also help the E by E to understand your loved one, and to find out what your views are about the current treatment and the future after discharge.

The E by E is there to listen to you and make sure that your voice is heard. S/he may also want to speak to your loved one either together with you or separately and will ask you to give your opinions about the following questions:

Confidentiality

All written and verbal information provided will be kept private and confidential, and will not be shared with anyone outside the meeting.

The review

Before you join the meeting, it is worth reflecting on the current guidance found on pages 12 onwards of the *Guide for CTR experts by experience* to clarify the purpose of the review and your important part within it:

- A CTR is an independent review of a person's care. It checks that people are safe and getting the right care for them, that they have good care plans for the future and that any problems with their health, safety or care get sorted out.

- The person has the right to be treated as an equal in their CTR and to have all the support they need to take part.

- A CTR is not just about a person's mental health or how they behave. It is about seeing the whole person, their quality of life, likes and dislikes, choices, hopes and fears.

- The person, and their family carers if taking part, should be fully involved and at the centre of the CTR.

- The panel will make time available to meet separately with the person and their family carers.

Taking part in the meeting

Try to be positive and stay calm. The meeting is led by the chairperson who will make sure that the meeting is run properly. Everyone will introduce themselves to start with.

The review team will have spent the first part of the meeting studying the notes and patient records, and finding out as much about your loved one and

their care as possible. The CTR is not an inspection of the provider, but the review team will be asking lots of questions and will have a role in constructively, but robustly, challenging inappropriate or ineffective practice, supporting cultural change and a shifting model to community care.

Questioning by the panel members will follow a set of key lines of enquiry (KLOE) to make sure that nothing is missed. Detailed minutes will not be taken, but the Chair will be responsible for logging key findings and recommendations in the assessment/report template that is used to record progress, concerns, barriers, actions and outcomes at the end of the day.

Each person will be asked about their own role in the person's care and support, and there will be time for everyone to ask questions. You will have an opportunity to have your say too. Follow your gut instincts where behaviour is concerned. You know your loved one best.

The review will be carried out in a consultative and informal manner, with the aim of supporting people to find solutions and unblock barriers to discharge.

The review team will discuss with the care team and the person whether there are more appropriate, effective and safe alternatives to hospital admission, or whether the person could be discharged from inpatient hospital care.

An inpatient CTR may last most of the working day and discussions may involve something like a dozen people. Neither you nor the person being reviewed has to attend for the whole meeting. The chairperson may wish to invite you to join the review soon after the meeting has started to avoid you sitting in the waiting room for too long, but there are no set rules about this as the agenda will vary depending on everyone's availability.

A Community CTR may also last for most of a working day and the format will be similar to an inpatient review. It will usually be held at the local offices of the commissioner or relevant LD team rather than a hospital.

If it is necessary to call an unplanned urgent Local Area Emergency Protocol review (for example, due to an impending crisis situation), the format, location and duration will depend on the circumstances, and you will be advised accordingly. In this situation not all the survival tips may apply, however consider all that are still helpful.

At the end of the review, the panel will agree and record actions and recommendations on the review template. They will then call back a number of the earlier attendees to share their findings and recommendations, and clarify who will do what by when.

Once you have left, on the way home (if not driving), make a note of outstanding issues or concerns to raise in the coming days with the commissioner, care coordinator or named nurse.

Meeting Survival Tips

- Don't forget to look after your own needs. Eat and drink something before you go.

- Double check the venue and the start time.

- Tell people where you are going and when you will be back.

- Allow time to get there. Aim to arrive about half an hour before it starts.

- Remember - the panel and staff are there to help you.

- One of the key aims today is to support people to find solutions and unblock barriers to discharge.

- Remember the review is not to apportion blame or raise complaints.

- Switch your phone to silent if you have it with you in the meeting.

- If you prepared a list of things to ask at the meeting, let the chairperson know first.

- Don't be afraid to ask what everyone's role is at the CTR.

- Stay calm, listen and make notes or jot down questions on your note pad if you wish.

- The meeting will last for most of the day. It is completely up to you how long you stay.

- Tell them what has helped your family member now and in the past and what you think could help them in the future.

- If you feel you need a break at any stage let the chairperson know.

- For an inpatient review, if it isn't clear, ask if a discharge plan is in place and if so what the challenges and timescale are.

- Ask the chairperson what the next steps are and to keep you informed. Also ask who to contact if you have anything else you want to ask about.

- Don't forget to retrieve your belongings on the way out.

Further information

Additional information on the CTR process can be found in the following publications:

My Care and Treatment Review
https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review.pdf

Care and Treatment Reviews (CTRs): Policies and Guidance
https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf
(please see page 24)

After the CTR

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What happens next?

The commissioner will now go away and complete the report. Hopefully, you will receive a thank you letter, which should also outline how you will be kept informed of progress.

Within a week of the CTR, the person will be supported to fill in the feedback form in their CTR Planner booklet by someone they choose, if they wish.

Everyone who took part in the meeting will be sent a copy of the finished report within two weeks of the review. This should include those helping with actions (for example, the Care Programme Approach (CPA) Care Co-ordinator or provider named nurse). The completed Excel review template containing recommendations and actions will be submitted and stored securely as part of the individual's medical record.

NB: If you don't receive the report within two weeks of the CTR, contact the care manager or the commission responsible.

The commissioner or nominated person will try and make sure that everyone is kept informed of progress regularly. They will also check that all recommendations are followed up and the action plan completed within the agreed timetable.

If there are any concerns that recommendations are not being achieved, the commissioner will escalate these in accordance with local policy and procedures.

The commissioner will also follow up on any specific quality or safeguarding concerns identified during the review to make sure that they are dealt with appropriately. Feedback will be given to the panel members as appropriate.

After a Community CTR

If you are caring for your son or daughter at home, it is vital that you all get the right support to avoid a further crisis situation developing. This was the whole point of the review after all.

Try to work as closely and constructively with the care team as possible to help complete the actions and recommendations that have been outlined. If problems emerge, don't struggle. You can't do it all yourself. If something is not right, let the care coordinator and the provider know straightaway. Make

sure you spell out what is happening, the risks and the resulting impact on the family. Keep a record of all issues in your diary and copies of all correspondence. This may be stating the obvious, but it is very important to maintain evidence, including the timeline, just in case.

Make sure you have easy access to the contact details of the local services and team members supporting you, including crisis intervention support. It would be a good idea to have a crisis plan ready and to share it with your team. You can find our Crisis Planning Guide and template _here_.

If your son or daughter lives elsewhere, for example in supported living or a residential setting, try to work positively with the Care Provider. Depending on the age of the person and consent if this is required, offer them the benefit of your lived experience and knowledge. This can be a difficult situation as the Care Provider is responsible for the care they provide and sadly, once young people reach the age of 16, your rights as parents diminish substantially. However, a good provider will try their best to work in partnership with you as much as possible.

To make this work, there has to be mutual respect and trust between you and the provider. Sometimes, it may feel as if this is almost impossible to maintain and this can result in mistrust, arguments and ill will. Share concerns with the care coordinator. If unsure, you can get some support here.

After an Inpatient CTR

The main aims of the CTR is to make sure that the care being provided is person-centred and meets the needs of the individual. It also ensures that any care and treatment facilitates discharge as soon as possible.

In hospital, ongoing assessment, treatment and care will be governed by day-to-day needs, local policies and procedures. The CTR recommendations and action plan, however, are key to driving everything forward, and must be supported and monitored closely by the CPA/commissioning teams to avoid the development of further problems and delays.

Try to maintain a good relationship with the Unit care coordinator or hospital liaison nurse. Assuming consent is appropriate, ask if they would be able to give you regular updates on progress. The CTR report does not personally give you any authority to try to hold others to account, but you have a huge amount of lived experience to share and have plenty to offer in a spirit of partnership and mutual support.

Ask if there are any significant issues or health problems and monitor activities and the outcomes of CPA meetings. Ask if there has been any advocacy involvement and, if so, what about? If you are concerned about

anything, speak to the CPA care coordinator or team manager. If problems persist, also let the commissioner's office know.

Disagreements and escalation of concerns

Refer to the <u>Care and Treatment Reviews (CTRs): Policy and Guidance document</u> (page 46 for CTRs and page 81 for CETRs) for details including:

- Clinical disagreements;

- Disagreements and escalation of concerns;

- Responsibility for escalating concerns; and

- Complaints relating to the CTR process.

Tips for the future

- Go through your notes from the review meeting and follow up anything outstanding.

- Keep a diary of appointments, meetings and decisions made.

- Check that the 'My CTR planner' booklet is being used effectively.

- **Get some support** in understanding the actions and outcomes of the review <u>here</u>.

- Ask the clinical team for regular updates on progress.

- Raise issues about care or support promptly with the care coordinator and provider.

- Maintain an up to date list of all active contacts and keep it to hand.

- Ask if providers/carers/support workers are trained in Positive Behaviour Support.

- If you are a carer, check you have had a carer's assessment.

- Check you have had a carer's health check in the last 12 months.

- Find out the details of local carers support groups and organisation.

Complaints about care should be made using the local policy.

Further information

It is worth repeating that the new *My Care and Treatment Review* booklet contains lots of helpful information about the whole CTR process from start to finish, including some very good tools about life after hospital including:

• How can I use my CTR report? (page 12); and

• Good standards for leaving hospital (pages 15 to 18) *https:// www.england.nhs.uk/publication/my-care-and-treatment-review/*

The easy-read version of this guidance is also available: *https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review-symbol.pdf*

The *My CTR Planner* booklet includes a *My CTR Report* on page 14 to help record the actions from the review. *https://www.england.nhs.uk/publication/my-care-and-treatment-review-planner/*

Other helpful resources

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Rights
Disability Rights UK
https://www.disabilityrightsuk.org**/**

Sectioning
Explains the rights that you have if you are sectioned and detained in hospital under the Mental Health Act 1983. Applies to England and Wales.
https://mind.org.uk/information-support/legal-rights/sectioning/
#.WQznUDEkuUk

Mental Health Act 1983
https://www.rethink.org/living-with-mental-illness/mental-health-laws/
mental-health-act-1983

Restraint
NICE Guidance NG10 - Violence and aggression: short-term management in mental health, health and community settings
https://www.nice.org.uk/guidance/ng10

Helping health and care services manage difficult patient behaviour
https://www.gov.uk/government/publications/positive-and-proactive-care-
reducing-restrictive-interventions

Education
SEND: guide for parents and carers
https://www.gov.uk/government/publications/send-guide-for-parents-and-
carers

Disability Rights UK - Links to key documents: Children and Families Act (2014)
https://www.disabilityrightsuk.org/links-key-documents-children-and-families-
act-2014

Local Offer:
http://bringingustogether.org.uk/local-offer-in-your-area/

Contact a Family - Education beyond 16
https://www.cafamily.org.uk/advice-and-support/sen-national-advice-service/
education-beyond-16/

IPSEA - Independent Parental Special Education Advice
https://www.ipsea.org.uk/

Abbreviations

AC	Approved Clinician
AHP	Allied Health Professionals
AMHP	Approved Mental Health Professional
AMHT	Area Mental Health Team
AOT	Assertive Outreach Team
ASD	Autistic Spectrum Disorder
ASW	Approved Social Worker
ATU	Assessment and Treatment Unit
CAMHS	Child and Adolescent Mental Health Services
CCG	Clinical Commissioning Group
CM	Care Management
CMHT	Community Mental Health Team
COP	Code of Practice (MHA)
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse
CRHT	Crisis Resolution and Home Treatment
CTO	Community Treatment Order
CETR	Care, Education and Treatment Review
CTR	Care and Treatment Review
DOLS	Deprivation of Liberty Safeguards
DSPD	Dangerous and Severe Personality Disorder
E by E	Expert by Experience
EIS	Early Intervention Service
GP	General Practitioner
HCSW	Healthcare Support Worker
HRA	Human Rights Act
IAPT	Improving Access to Psychological Therapies
ICT	Integrated Care Team
IMCA	Independent Mental Capacity Advocate
IMHA	Independent Mental Health Advocate

IST	Intensive Support Team
KLOE	Key Lines of Enquiry
LA	Local Authority
LSE	Low Stimulus Environment
MAT	Multi-agency Team
MDT	Multi-disciplinary Team
MHA	Mental Health Act
MSU	Medium Secure Unit
NICE	National Institute for Clinical Excellence
NN	Named Nurse
NR	Nearest Relative
OT	Occupational Therapist
PALS	Patient Advice and Liaison Service
PBS	Positive Behaviour Support
PCT	Primary Care Trust
Physio	Physiotherapist or Physiotherapy Treatment
PICU	Psychiatric Intensive Care Unit
PRN	Pro Re Nata (as required)
RC	Responsible Clinician
RCGP	Royal College of General Practitioners
Referral	Request or application for a service
RiO	Trust Electronic Patient Record
RMHN	Registered Mental Health Nurse
SaLT	Speech and Language Therapy/Therapist
SCR	Secondary Care Record
SCT	Supervised Community Treatment (also known as a Community Treatment Order)
Sectioned	Commonly used term for a person detained under Mental Health legislation.
SOAD	Second opinion appointed doctor
SU	Service User (polite method of referring to psychiatric patients)
SW	Social Worker
WRAP	Wellness Recovery Action Plan

Contacts List

Name	
Position	
Address:	
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Email	

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Address:	
Tel No	
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Key Documents

Care and Treatment Reviews
https://www.england.nhs.uk/learning-disabilities/ctr/

Care and Treatment Reviews (CTRs): Policy and Guidance March 2017
https://www.england.nhs.uk/publication/care-and-treatment-reviews-policy-and-guidance/

Key Changes in the CTR policy
https://www.england.nhs.uk/learning-disabilities/ctr/ctr-policy-changes/

CTR/CETR Code and Toolkit
https://www.england.nhs.uk/publication/care-and-treatment-review-code-and-toolkit/

CTR Guidance and Tools for Commissioners, Panels and People providing Care
https://www.england.nhs.uk/learning-disabilities/ctr/commissioners/

Care Education and Treatment Review Code and Toolkit
A guide for commissioners, panel members and people who provide support
https://www.england.nhs.uk/wp-content/uploads/2017/03/children-young-people-cetr-code-toolkit.pdf

Care and Treatment Reviews - Frequently Asked Questions
https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/04/ctr-faqs.pdf

Easy Read Information
https://www.england.nhs.uk/learning-disabilities/ctr/support/er/

My Care and Treatment Review (CTR)
https://www.england.nhs.uk/learning-disabilities/ctr/my-ctr/

Care and Treatment Review: Key Lines of Enquiry
https://www.england.nhs.uk/publication/care-and-treatment-review-key-lines-of-enquiry/

Expert by Experience Booklet
https://www.england.nhs.uk/publication/expert-by-experience-booklet/

Local Area Emergency Protocol, in Care and Treatment Reviews (CTRs): Policy and Guidance (page 102)
https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf

Meeting the Challenge - Guides for Families
Guides on getting the right support for people with a learning disability and behaviour that challenges.
https://www.mencap.org.uk/advice-and-support/displaying-challenging-behaviour/meeting-challenge-guides-families

Sectioning
Provides overview of rights under the Mental Health Act, 1983.
https://www.mind.org.uk/information-support/legal-rights/sectioning/overview/#.WQ3zVoWcF9B

Consent to Medical Treatment
http://www.mind.org.uk/information-support/legal-rights/consent-to-treatment/consent-to-treatment/#.WPu0TTEkuUl

Transforming Care. Model Service Specifications: Supporting Implementation of the Service Model
https://www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf

Psychiatric Medication
https://www.mind.org.uk/information-support/drugs-and-treatments/medication/coping-with-side-effects/#.WQ4XZYWcF9B

Psychotropic Drug Prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge practice guidelines
https://www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf

Getting Help in a Crisis
https://www.rethink.org/carers-family-friends/what-you-need-to-know/getting-help-in-a-crisis

The Mind Guide to Crisis Services
http://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/#.WN-NHTGguUk

NICE Quality statement 9: Crisis Planning
https://www.nice.org.uk/guidance/qs14/chapter/Quality-statement-9-Crisis-planning

Advocacy in Mental Health
https://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/#.WQ3w34WcF9D

Mental Capacity and Mental Illness
https://www.rethink.org/living-with-mental-illness/mental-health-laws/mental-capacity

Mental Capacity Act 2005
http://www.mind.org.uk/information-support/legal-rights/mental-capacity-act-2005/overview/#.WPkKZ4WcF9A

What do 'mental capacity' and 'best interests' mean?
http://sites.cardiff.ac.uk/wccop/resources/3-what-do-mental-capacity-and-best-interests-mean/

How do we plan for a successful discharge for my family member?
http://www.challengingbehaviour.org.uk/learning-disability-files/6-How-do-we-plan-for-a-successful-discharge-for-my-family-member.pdf

Getting it right for people with learning disabilities
http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Documents/NHS-England-Getting-it-right-for-people-with-learning-disabilities-epublication.pdf

Transition between inpatient mental health settings and community or care home settings NICE guideline [NG53]
https://www.nice.org.uk/guidance/ng53/chapter/Recommendations

Together Matters: Planning for the Future
A group that aims to improve lives for people with learning disabilities and their families.
http://www.togethermatters.org.uk/

Disability Law Service
Offers free legal advice to disabled people and their carers.
http://dls.org.uk/

Independence Pack
Two new resources to help patients in specialist learning disability or mental health hospital services to plan for leaving hospital.
http://www.changepeople.org/blog/february-2016/independence-pack

Learning disability and autism resources

Transforming Care for People with Learning Disabilities
– Next Steps
https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

Building the Right Support
https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition (Service model for commissioners of health and social care services)
https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

Green Light Toolkit: Mental Health Services and Support for People with Autism and People with Learning Disabilities
https://www.ndti.org.uk/our-work/our-projects/past/green-light-toolkit-2013

Supporting staff working with people who challenge services:
Guidance for employers (February 2013)
http://www.skillsforcare.org.uk/Document-library/Skills/People-whose-behaviour-challenges/Supporting-staff-working-with-challenging-behaviour-(Guide-for-employers)vfw-(June-2013).pdf

Best practice information and resources for carers working with people with autism. Skills for Care:
http://www.skillsforcare.org.uk/Topics/Autism/Autism.aspx

Royal College of GPs' information on Autistic Spectrum Disorders:
http://www.rcgp.org.uk/clinical-and-research/clinical-resources/autistic-spectrum-disorder.aspx

Autism Skills and Knowledge List, for workers in generic social care and health services. Part of the 'Better social care and health outcomes for people with autism' series.
http://www.skillsforcare.org.uk/Documents/Topics/Autism/Autism-skills-and-knowledge-list.pdf

Health Education England
Best practice information and resources for health and care staff:
https://hee.nhs.uk/our-work/hospitals-primary-community-care/mental-health-learning-disability/learning-disability/autism

Positive Behaviour Support

Guidance and best practice information on positive behaviour support for carers. Skills for Care:
http://www.skillsforcare.org.uk/Topics/Learning-disability/Positive-behavioural-support/Positive-behaviour-support.aspx

Positive Behavioural *Support: A Competence Framework. Positive Behavioural Support (PBS) Coalition UK*:
http://www.skillsforcare.org.uk/Documents/Topics/PBS/Positive-behavioural-support-competence-framework.pdf

Mini Guide to Positive Behavioural Support Training. Arranging and paying for training in positive behaviour support. Skills for Care and Skills for Health (June 2016):
http://www.skillsforcare.org.uk/Documents/Topics/PBS/Mini-guide-to-Positive-behavioural-support-training.pdf

PBS Academy
Group of organisations and individuals promoting PBS for people learning disabilities who are at risk of behaviour that challenges:
http://pbsacademy.org.uk/

Mental Health

Rethink Mental Illness Factsheet Library
https://www.rethink.org/advice?utm_source=email&utm_medium=informz&utm_campaign=blank

Learning Disabilities: identifying & managing mental health problems NICE [QS142]
https://www.nice.org.uk/guidance/qs142

My Personal Health Record

This personal health record is designed to help your loved one to make sure their physical health is not affected by the medication they are taking (for example, anti-psychotic, anti-depressant and benzodiazepine medication. These medications can help manage anxiety, stress and psychosis, but can have possible side effects (such as weight gain, which can lead to obesity and an increased chance of developing type 2 diabetes). Healthy lifestyle choices can also help keep your loved ones in good physical health. If there is anything you are not sure about, ask your loved one's GP or Responsible Clinician (RC).

It is important to have blood tests, an ECG and get weighed before they start medication, and these should be repeated regularly during the early stages of treatment.

Below is a table to help monitor your loved one's treatment.

My Personal Health Record				
Name				
D.O.B.				
GP Surgery				
Allergies				
Medication	Dose	Frequency	Date started	Date Stopped and reason why

Below you can record your lived ones' test results to help you monitor how they are progressing. You can ask your GP or RC for help in completing the table. This will help identify any problems arising and facilitate a medication review. It may be necessary to change or stop your loved one's medication if it is affecting their physical health and well-being.

Health Test Results				
Date				
Height (cm)				
Weight (kg)				
BMI				
ECG				
Heart Rate				
Blood Pressure				
HbA$_1$C				
Total Cholesterol				
Prolactin				
LDL				
Cortisol				

To help you understand the test results above, the next table shows you what the ideal test results should be. Please speak to your loved one's GP if you need help understanding the results below.

Optimum Healthy Ranges	
BMI	18.5 – 24.9
Blood Pressure	140/90
HbA$_1$C (non-diabetic)	Less than 42
HbA$_1$C (diabetic)	47 – 58
Total Cholesterol	5 or less
Prolactin	Less than 400
LDL	3 or less

Please visit NHS Choices for further advice on medication, healthy diet and exercise. www.nhs.uk/Pages/HomePage.aspx

With thanks to:

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Disclaimer:

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