

Care (Education) & Treatment Reviews and Dynamic Support Registers



Created by families

Updated - April 2024

TABLE OF CONTENTS



1

INTRODUCTION **4**

How to use this guide **4**

New Policy, key differences **5**

Dynamic Support Registers **7**

2

THE C(E)TR PROCESS **11**

What is a C(E)TR? **11**

Requesting a C(E)TR **12**

When is a C(E)TR held & how often can you have one? **13**

What happens in a C(E)TR? **17**

Who does what? **18**

What makes a good C(E)TR? **21**

SMART outcomes **23**

Keyworker **23**

Family Ambassador **24**

LAEP meetings **25**

Role of Advocacy **27**

3

BEFORE THE DAY: PREPARING FOR C(E)TR **28**

What to expect - A typical agenda **29**

Person-centred plans **31**

Carer's Monitoring Form **32**

Carer Contingency Planning **32**

4

WHAT ARE MY RIGHTS? **33**

TABLE OF CONTENTS CONTINUED



5

LOOKING AFTER YOURSELF **34**

6

ON THE DAY: AT THE C(E)TR **35**

Confidentiality **36**

The review **36**

Physical Health **37**

Medication **37**

Your Role as Family Member **39**

Meeting survival tips **40**

Feedback session **40**

Key questions to ask **41**

7

AFTER THE DAY: FOLLOWING THE C(E)TR **42**

What happens next **42**

When should the report come out **42**

After a community C(E)TR **43**

After an inpatient C(E)TR **43**

Disagreements and escalation of concerns **44**

Groups to contact for support **45**

8

REFERENCE SECTION **46**

Key documents **46**

Resources **49**

Jargon Buster **51**

Acknowledgments **53**

Disclaimer **54**

INTRODUCTION



Welcome to our family survival guide to Care (Education) and Treatment Reviews referred to as C(E)TRs, and The Dynamic Support Register, referred to as DSRs. This guide has been written to help families understand these processes.

The guide focuses on the period before, during and after a C(E)TR, and also covers related topics to help you understand the process. It is based on NHS England's Dynamic Support Register and Care (Education) and Treatment Review Policy and Guide, which came into effect in May 2023, so this is an updated version of the previous Family Survival Guide from 2017 to reflect the changes.

This guide has been developed with the help of some very dedicated parents and families of autistic people and people with learning disabilities, who have experienced their loved ones being an in-patient in a mental health hospital.

A separate guide has also been written to help children and young people understand and make decisions about the C(E)TR process and Dynamic Support Register.

HOW TO USE THIS GUIDE

The information has been arranged to support families at any stage in the DSR and the C(E)TR processes. 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 of this guide will help you carry out further research as needed.

The guide has been colour-coded to make it easier for you to find your way around it. If you are using the online version then you can quickly access the section you need from the contents page, by clicking on the relevant page number. To return to the contents page, click the top right corner image.

INTRODUCTION



We hope this guide helps you understand what a DSR is, helps you prepare for a C(E)TR and know what to expect. We have put explanations in the reference section for some jargon words that you may not be familiar with.

In the online document click on words in blue type for further information. If you print this document you will find all links in the reference section from page 46.

This updated survival guide will include some very important changes to ensure that families are aware of what to expect from the C(E)TR and DSR processes.

The main changes in the updated guidance are:

- 1) The right to self-refer
- 2) The minimum requirements for DSRs
- 3) The new Key Lines of Enquiry (KLOE) report following the C(E)TR
- 4) The greater emphasis on the voice of the family
- 5) The role of the Keyworker
- 6) The role of the Family Ambassador
- 7) Focus on physical health
- 8) Greater focus on advocacy

It's important to remember that this guide is based on policy and guidance from NHS England. The guidance sets out what should happen and what must happen, it also sets out timescales - when things should happen, but the responsibility for working out *how* things actually happen is left to each Integrated Care Board (ICB) in each Integrated Care System (ICS). This is so that the way that things are set up fits in with how services work in different parts of the country.

Please make use of this guide to find the information you need to work with your local services if and when you need to, so that the C(E)TR process works properly.

INTRODUCTION



“The new policy is to support people to work better together so that people with a learning disability and autistic people get the right support to stay well and have a good life”

Dr Roger Banks, former National Clinical Director.

You will find a link to the DSR and C(E)TR Policy and Guidance and also the easy read version on [page 41](#) of this guide.

Here are some of the changes that have been implemented following the updated guidance from 2023:

VOICE OF FAMILY TO HAVE GREATER EMPHASIS

This was agreed as part of the new policy to ensure that families/carers are listened to and that their voices are heard, it recognises the importance of your role to ensure the best outcome for your family member.

FOCUS ON QUALITY OF LIFE

These new C(E)TR and DSR processes take an approach that looks at whether the person is being supported to have as good a quality of life as possible. For example:

- Are they being enabled to stay in contact with their family and with friends?
- Can they carry on with hobbies that they enjoy?
- Are their cultural needs being met?
- Is their future being considered and is there a wider life plan?

NB: Throughout this guide, when we refer to C(E)TRs, the information will also apply to CTRs unless otherwise stated.

CTRs are for people who aren't in education anymore.



THE DYNAMIC SUPPORT REGISTER

The DSR is the mechanism that local systems use to:

- identify people at risk of admission to a mental health hospital
- work together to review the needs of each person registered on the DSR
- mobilise the right support (eg a C(E)TR, referral to a keyworker service for children and young people, extra support at home) to help prevent the person being admitted to a mental health hospital.

The DSR enables systems to identify adults, children and young people with increasing and/or complex health and care needs who may require extra support, care and treatment in the community as a safe and effective alternative to admission to a mental health hospital. They also play a role in ensuring that people's needs are included in commissioning plans, financial plans, service delivery and development.

The aim of both DSR's and C(E)TR's is to prevent autistic people and those with a learning disability being admitted to Mental Health inpatient hospitals where possible.

If someone has already been admitted to hospital, the aim is to support the person to become well enough to leave hospital as soon as they no longer require care and treatment in a hospital setting. This may include ensuring the right support in the community to ensure the person is safe, and a good robust transition process to an environment that is appropriate for them to prevent re-admission.

For any person to be included on a DSR, consent needs to be given and formally documented. If the person is under 16, they can consent if they are able to fully understand what is involved, otherwise someone with parental responsibility needs to consent on their behalf. Either way, families should be involved in the decision making unless there are clear and formally documented reasons not to do this.

NHS England have created leaflets designed for young people (aged 16 to 25 years) to help them make informed decisions about being on the DSR and having a C(E)TR. Click [HERE](#) to open a link to these leaflets.



THE DYNAMIC SUPPORT REGISTER

Right to self refer:

As well as being referred by professionals, individuals can now self-refer to their local area dynamic support register (DSR).

Integrated care boards are accountable for the DSR across their area. Local areas must have processes in place for receiving all referrals to be added onto the DSR. This process should include letting the person being referred know that the referral has been received. Where the person making the referral is someone else, they should also be notified that it has been received. Notification of receipt should take place within five working days.

Local areas must publish their criteria, process and point of contacts for both DSRs and C(E)TRs on local integrated care board websites, including the Local Offer website for special educational needs and disability (SEND).

A key benefit of being on the DSR is that the person's care is reviewed at regular meetings because their wellbeing is flagged as being 'at risk'.

Risk Stratification process

The risk stratification or 'RAG' rating process is a tool that local areas must use to work out the level of risk a person is facing.

This must take account of:

1. The person's view about their current situation
2. The family's view about the current situation
3. Risk assessments already in place

The person may need and be entitled to advocacy support to give their view. Families should consider seeking support from local parent carer forums and other local support services.

For people up to the age of 25, the DSR can also be a gateway to getting a Keyworker. The Keyworker is a new role which is a key element of the updated policy and guidance. Keyworkers are being called 'game changers' by many families who have benefitted from working with them. Click the link or go to [page 23](#) to find out more about the role.

INTRODUCTION



This infographic from NHS England aims to explain what the DSR is for and how this connects with C(E)TRs.

The purpose of the register is to provide a way for professionals to work together to identify people in need of extra support and to help each person get the support they and their families need, when they need it.

Supporting people with a learning disability and autistic people to get the right care, at the right time, in the right place



More people cared for at home

Dynamic support registers (DSR)

- For adults, children and young people
- A tool used in a local area to identify people at risk or may become at risk of admission to a mental health hospital setting without specific and timely dynamic support.
- Each person is given a **RED**, **AMBER** or **GREEN** rating dependent on risk - or **BLUE**, a separate rating identifying those children, young people and adults currently in inpatient services.



Care (Education) and Treatment Review (CETR)

- For adults, children and young people
- A meeting to talk about people at risk of going into a mental health hospital and who are already in a mental health hospital.
- Make sure the person and their family are listened to.
- Makes a plan to support people to get the treatment they need.
- Each time a C(E)TR takes place, a review of the red, amber or green rating on the DSR takes place.
- A record of C(E)TR recommendations kept on the DSR record.
- The dynamic support risk stratification process should include a review of community C(E)TR recommendations and inpatient C(E)TR recommendations for people at risk of readmission.

INTRODUCTION



This infographic explains the 'RAG' (Red, Amber and Green) rating system. This shows how the risks people face are rated to determine what level of support they need. For example, if they are rated red or amber on the DSR they should have a C(E)TR and for children and young people they should be allocated a keyworker

RED

There is an immediate risk that the person will be admitted to a mental health hospital.

The person and/or their family are experiencing a crisis and the risk of admission to a mental health hospital are not being or cannot be managed in the community.

Linked processes:

- a C(E)TR must take place (see part B)
- referral to the keyworker service (for people aged 0–25 years) if the person is not already known to this service.

AMBER

There will be an immediate risk that the person will be admitted to a mental health hospital without urgent intervention.

There could be a significantly increased risk of the person becoming mentally unwell and/or placement/family breakdown.

Linked processes:

- multi-agency meeting and/or C(E)TR
- referral to the keyworker service (0–25 years), if not already known to this service.

GREEN

There are some risks that could lead to the person being admitted or re-admitted to a mental health hospital; but currently these risks are being effectively managed.

Linked process:

- clear identification of partners who would need to be involved in a C(E)TR if required.

BLUE

A separate rating must identify those children, young people and adults currently in inpatient services.

Linked processes:

- this rating should be used to identify people requiring commissioner oversight visits and inpatient C(E)TRs.

THE C(E)TR PROCESS



WHAT IS A C(E)TR?

Care (Education) and Treatment Reviews (C(E)TRs) are an essential person-centred process, for people who are in crisis, people heading towards crisis or where people have recently been in crisis. They seek to ensure system partners are working with people and families to provide the right care, education and treatment to avoid the need for an admission to a mental health hospital and ensure good care for all.

C(E)TRs were introduced to independently review the care, support, and treatment of autistic people and people with a learning disability, where their support is at risk of breaking down in the community, they are at risk of needing to be admitted to a mental health hospital or they are already an in-patient.

Its purpose is to ensure the care, (education), treatment and support needs of the individual person and their family are being met, and that barriers to progress and/or discharge from hospital are challenged and overcome.

There are two versions of the Care and Treatment Review. One is for adults and is still known as a Care and Treatment Review (CTR). A CTR may be held for any autistic person or person with a learning disability, who may be at risk of admission to, or who is already in a specialist learning disability or mental health hospital.

The other is for children and young people and is called a Care, Education and Treatment Review (CETR). Both use the same toolkit, though if you have a CETR, education must be involved. Here is the link to the [toolkit](#).

The review is led by the Chair with support from two independent expert advisers. One of the expert advisers is an expert by experience; this means someone with relevant lived experience or a family member of someone with relevant lived experience. Their role is to bring constructive challenge, alternative perspectives and solutions. The review Panel makes recommendations to improve the person's care, education and treatment with follow up checks to make sure this is happening.

The C(E)TR should last a full day (usually from 9am to 5pm).

THE C(E)TR PROCESS



REQUESTING A C(E)TR

The request for a C(E)TR can be made by any of the following people:

- The person
- The person's family
- An advocate or any other professional such as Head Teacher or SENCO
- The clinical team
- The commissioner

C(E)TRs can be requested both for people living in the community and those who have been admitted to hospital, whenever there are concerns about the suitability of a service, the treatment plan, the individual's safety and wellbeing and for inpatients, where there is no clear discharge or transfer date and plan. The C(E)TR is designed to respond to the needs of people who are facing a crisis in their mental health.

The process for requesting a C(E)TR should be set out on the local offer (ICS/ICB) website. If it's not there, find the email address for the Integrated Care Board (ICB) and send an email to the 'Executive lead for Learning Disabilities and Autism'. Their first response should be to address the concerns that led to the request as promptly and thoroughly as possible. This may include trying to arrange additional support if the concern relates to possible hospital admission, so potentially avoiding the need for admission and a C(E)TR. [Here](#) is the code of practice.

Local areas must have a process for requesting a C(E)TR; this process should include how they reach their decisions and whether an appeal can be made when a request for one is denied. There should also be a process for how decisions are recorded and communicated to the person and their family.

Where it is decided that a C(E)TR will not benefit the person but the referrer continues to feel one is necessary and appeals against the decision, the request should be escalated to the commissioner to consider in line with locally established protocols. C(E)TR requests should not be regarded as a form of complaint and should not be handled through usual complaints channels.

THE C(E)TR PROCESS



WHEN IS A C(E)TR HELD & HOW OFTEN CAN YOU HAVE ONE?

What triggers a Care (Education) and Treatment Review?

[Section 13 of the policy](#) includes clear descriptors of the triggers for a Care (Education) and Treatment Review (C(E)TR). Children, young people and adults who identify as red and amber on the dynamic support register (DSR) trigger a C(E)TR as they have been identified as at risk of admission into mental health inpatient settings.

New triggers for a C(E)TR, are included in 13.1 of the policy:

- Six weeks after admission to hospital if a community C(E)TR has been undertaken.
- If a person is transferred to another hospital or to a setting within the same hospital with a different security level.
- If a person receives a diagnosis of autism or a learning disability during their admission in hospital.
- If a clinical review identifies that someone has been incorrectly diagnosed with autism or a learning disability and removal of the diagnosis is proposed.

People are also able to request a C(E)TR outside of these timescales and trigger points.

For a repeat C(E)TR, the person should be asked whether they would prefer to have the same panel (where possible) to undertake their next one. However, there may be cases where it is considered beneficial to use a different panel.

The Expert by Experience and the Clinical Reviewer will always be independent. The Chair will either be the local Commissioner or a person who has delegated commissioning responsibility.

THE C(E)TR PROCESS



The tables that follow set out when a person should have a C(E)TR and if applicable, when the next one should take place.

C(E)TR pathway for children and young people up to 25 if education health and care plan in place or if the young person remains in the CYP mental health tier 4 hospital (post 18 years)			
Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
Community C(E)TR	Prior to admission	6 weeks after admission and then 3 monthly (unless hospital transfer occurs)	Additional CETR if other trigger points hit
No community C(E)TR (or LAEP)	CETR within 14 days (10 working days)	3 monthly (unless hospital transfer occurs)	Additional CETR if other trigger points hit

C(E)TR pathway (all ages) for person diagnosed as autistic or having a learning disability while in hospital			
Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
C(E)TR	Refer to post-admission timescales: 28 days (20 working days) for adults and 14 days (10 working days) for children and young people	C(E)TRs to continue as per minimum timescales for relevant pathway	

THE C(E)TR PROCESS



CTR pathway (all ages) for removal of a diagnosis of autism or a learning disability is being considered during an inpatient stay

Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
C(E)TR	C(E)TR to be undertaken prior to any diagnostic changes being formally made		Recommendations to consider impact of diagnostic changes and possible removal from Assuring Transformation for individual

CTR pathway (all ages) for person identified as requiring hospital transfer and/or change in security settings within the same hospital

Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
C(E)TR	Within 6 weeks of transfer	C(E)TRs to continue as per minimum timescales for relevant pathway	

CTR pathway for adults in non-secure services, including acute mental health, rehab, assessment and treatment

Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
Community CTR	Prior to admission	6 weeks after admission and then 6 monthly (unless hospital transfer occurs)	Additional CTRs if other trigger points hit
No community CTR (or local area emergency protocol (LAEP))	Post-admission CTR within 28 days (20 working days)	6 monthly (unless hospital transfer occurs)	Additional CTRs if other trigger points hit

THE C(E)TR PROCESS



CTR pathway for adults in secure services via non-criminal justice route

Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
Community CTR	Prior to admission	6 weeks after admission and then 12 monthly (unless hospital transfer occurs)	Additional CTRs if other trigger points hit
No community CTR (or LAEP)	Post admission CTR within 28 days (20 working days)	12 monthly (unless hospital transfer occurs)	Additional CTRs if other trigger points hit

CTR pathway for adults in secure services via criminal justice route (prison or court)

Type of review	Maximum time for completion	Maximum frequency of repeat reviews	Notes
Exempt from community CTR	Post-admission CTR within 28 days (20 working days)	12 monthly (unless hospital transfer occurs)	Additional CTRs if other trigger points hit

WHAT HAPPENS IN A C(E)TR?

Organising a C(E)TR

Before the meeting takes place, the commissioner/chairperson will have made sure that the appropriate consent has been obtained from the person being reviewed, or from their parents if the person is under 16. The agenda should have been finalised before the C(E)TR so that everyone knows when to attend, for how long and what their contribution is expected to be.

If the person is 16 or over and does not have capacity to give consent, this should be sought from a parent (if the person is under 18), someone with Lasting Power of Attorney or a court appointed health and welfare deputy. Otherwise, a best interests decision to continue the review should have been made under the Mental Capacity Act.

THE C(E)TR PROCESS



The chairperson is responsible for identifying and ensuring the following:

- that any reasonable adjustments are made for the C(E)TR
- any requirements for specific experts, eg. gender specific or autism
- arranging a date that's convenient for the person and their family
- providing enough time (ideally two weeks) for the person and their family to give consent and decide who they want to invite to their C(E)TR
- that the person has time booked in to meet with the chairperson or their service provider to prepare for the C(E)TR
- all panel members have agendas and paperwork sent to them in advance.

Planning should also include confirming whether anyone will be joining by video conference (eg. Microsoft Teams) if the meeting is being held as hybrid (ie. some people are on-line and some face to face). The C(E)TR Panel will have read the person's notes to learn about who they are as a person as well as their care and treatment plans

During the C(E)TR

The agenda will outline the plan for the day. There will be a time slot for the person to meet the panel (only if the person agrees to it) and this may just be one or two members of the panel. Reasonable adjustments will be made wherever possible. If the person has an advocate, they may also attend. It is very important to hear everyone's views about the care and treatment being provided, and to make sure that their voices are heard.

There will then be a Multi-Disciplinary Team (MDT) session, sometimes this can be professionals joining separately but mostly as a group for the panel to ask questions to do with the person's care & treatment.

The review team will ask questions to understand the following:

- Is the person safe?
- Is the person receiving good care now?
- What are the person's care plans for the future?
- Can their care and treatment be safely provided in the community?

THE C(E)TR PROCESS



Under each of these 4 main headings are lists of other important questions which are known as [Key Lines of Enquiry \(KLOE's\)](#) – these help to guide the review process.

Once all attendees have been interviewed, the Panel – the Chair and the two independent experts - will discuss what they have heard and observed. Together, they will write up a detailed report based on the C(E)TR template. Recommendations must be clear, they have to state who is responsible for following through on actions and the date by which it should be completed.

At the end of the day, the chairperson will invite everyone back to give a verbal summary of the Panel's findings. The final written report will be sent by the chairperson to the person, their advocate (if one has been appointed), a family member and the care team within two weeks of the C(E)TR taking place.

WHO DOES WHAT?

The commissioner is responsible for the person's package of health care, making sure it meets the assessed needs of the patient through care and treatment. They work 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. This may include local authority colleagues or joint commissioners who will need to be involved in the review to make sure they can plan for the future and deal with any barriers to progress.

Recommendations from the C(E)TR should be shared with the DSR lead so that actions can be monitored in DSR multidisciplinary meetings covering health, social care and education. If the person doesn't consent to be on the DSR, local areas should consider how actions will be monitored.

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

THE C(E)TR PROCESS



The different individuals that attend the C(E)TR if appropriate are listed below, their role and function:

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.

(1) if the patient is 16 or older consent is required for a family member to attend

THE C(E)TR PROCESS



WHO DOES WHAT? CONTINUED...

The different individuals that may also attend the C(E)TR if appropriate.

Role	Function
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
Care Programme Approach Care Coordinator	Professional responsible for CPA planning, care and support.

THE C(E)TR PROCESS



WHAT MAKES A GOOD C(E)TR?

A C(E)TR that is person centred, action focused and has good outcomes for the person. The new policy that came into effect in May 2023 puts much more emphasis on this by keeping the person and their family at the heart of it.

A good C(E)TR should feel inclusive.

The C(E)TR should ensure that the person's physical, mental, social and emotional needs are understood and supported.

The person should feel seen as a whole person and that their rights have been acknowledged and respected. The principles of a good C(E)TR are outlined in the following acronym - 'PERSONAL':

- **P**erson (child, young person or adult) centred and family centred
- **E**vidence based
- **R**ights led
- **S**eeing the whole person
- **O**pen, independent, and challenging
- **N**othing about us without us
- **A**ction focused
- **L**iving life in the community

MY C(E)TR

There are two really useful booklets that can help to understand and plan the C(E)TR. They are called:

[My Care and Treatment Review](#) and [My C\(E\)TR Planner](#)

They can be found by clicking the links above.

There are also easy read versions of both booklets:

[My Care and Treatment Review Symbols](#). and
[My C\(E\)TR Planner \(easy read\)](#).

THE C(E)TR PROCESS



C(E)TR DOCUMENTS CHECKLIST

Before attending the C(E)TR meeting, the independent experts may know very little about the person, their background or the care being provided. This means they are completely independent and able to look at the whole situation with the objectivity a fresh pair of eyes can bring. They will therefore expect an information pack to be prepared and shared in advance of the meeting, so they can learn about the person quickly and comprehensively.

The C(E)TR chairperson will be responsible for ensuring that all written and verbal information provided will be kept private and **confidential** within the meeting. For a C(E)TR in a hospital, the responsibility for producing the pack is with the provider and for a Community C(E)TR it is the Commissioner's responsibility.

C(E)TR documents that will typically be needed can be found in the checklists below –

[Care \(Education\) and Treatment Review document checklist – community](#)

[Care \(Education\) and Treatment Review document checklist – inpatient](#)

KLOE'S (KEY LINES OF ENQUIRY)

Panel members are offered four different 'Key Lines of Enquiry' templates that include questions to help them make the C(E)TR process more person-centred. The four types of KLOE are:

1. Child Community
2. Adult Community
3. Inpatient Child
4. Inpatient Adult

You can find a list of these questions on pages 6 to 10 of the easy read guide:

[Easy read guide for children and young people in the community](#)

Using the KLOE's will generate recommendations and actions that can be shared with the person. Each template has an easy read version designed to support the person receiving the review.

THE C(E)TR PROCESS



SMART OUTCOMES

The recommendations made by the Panel need to be SMART to ensure accountability. SMART outcomes should answer questions along these lines:

Specific	What exactly should happen and what is 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.

KEYWORKER ROLE

The Keyworker role has been set up to provide person and family-centred support to the family carer as well as support to the child themselves, where they are at risk of admission to a mental health hospital.

The local Keyworker service should be linked to the DSR.

All children and young people with a learning disability, autism or both aged 0–25 years with the most complex needs should have a designated keyworker. Initially, children and young people who are inpatients or at risk of being admitted to hospital (as a minimum those with a red/amber rating on the DSR) should have access to support from the keyworker service.

THE C(E)TR PROCESS



Keyworkers support children, young people and their families to avoid admission to a mental health hospital wherever possible. Where admission to hospital cannot be avoided, the keyworker should remain as a core member of the professional network throughout the person's period of admission, and be included in CETRs and support through to discharge.

The role is:

- To ensure that children, young people and families get the right support at the right time
- To help families feel they are fully involved in plans and feel listened to
- To experience a reduction in stress and uncertainty and an increase in stability
- To ensure plans are person-centred and support is offered in a co-ordinated way.

Click this link for further information: [Children and young people keyworkers](#)

FAMILY AMBASSADOR ROLE

The family ambassador is a role that has been set up by NHS England to support a family carer when their child is receiving inpatient care (in a CAMHS/Tier 4 unit) to achieve a better outcome.

Their role is:

- To provide positive support from a family member with lived experience
- To help family carers understand and navigate the process from admission to discharge
- To answer any questions regarding the admission
- To support communication between the family and the unit
- To empower the family carer to enable their voice to be heard and to be part of the planning process
- To provide appropriate resources
- To signpost to other services/support groups.

For further information click the link here: [Family Ambassadors](#)



LOCAL AREA EMERGENCY PROTOCOL (LAEP) MEETINGS

A (LAEP) meeting may be called to try and stop your child from needing to go into a mental health hospital. Sometimes their support needs can change quickly when struggling with extremely distressed behaviours which may also be difficult or dangerous. It is important to remember that all behaviour is communication. All those involved must have a good understanding of autism and learning disability, to ensure that human rights based and person-centred support is given.

Sometimes there isn't time to arrange a care, education treatment review (CETR) and in these cases, there will be a LAEP meeting instead.

In the LAEP meeting there may be someone from your ICB commissioning team to chair, someone from your mental health support team, the person and their family.

All involved in the meeting will discuss:

- What is happening at the moment and what you want to happen for your child
- What your child or young person's health, care and support needs are
- Keeping your child and young person, you and others safe if there are any current risks.
- How best to work together to put in place where possible, the least restrictive options in your local community, a wrap around plan for your child or young person's care needs and for any support network involved.
- Also, a discussion might lead to your child or young person going into a mental health hospital if the situation is very urgent. The commissioner who will fund this specialist hospital, must share responsibilities and accountability to ensure the chosen hospital offers a safe, clearly therapeutic, trauma informed and autism friendly environment. All staff should be competent, compassionate, caring and have completed mandatory autism and learning disability training, preferably the government recommended [Oliver McGowan Mandatory training](#).

The overall aim of both LAEP and C(E)TR meetings is to try and support your child and young person in a crisis to continue to live in their local community and prevent a hospital admission.

THE C(E)TR PROCESS



If you want to know more about LAEP in your local area and find out more about how this meeting works, please contact your local Integrated Care Team and request information in your preferred format, including any reasonable adjustments you may have if you're a neurodiverse parent or a parent with a learning disability yourself.

Some 'Top tips' to help you prepare for your child's LAEP and/or C(E)TR meetings

- *Keep a record of your child or young person's past and current EHCP if they have one, Annual review documents, the child or young person's wishes and feelings that may be recorded in legal documents;*
- *Support plans which include what makes your child or young person frightened, upset, anxious, experience sensory overwhelm or shutdown, as well as what helps them feel well and what behaviour is normal for them;*
- *Reports from Speech and Language Therapists, Occupational Therapists, Psychology, school, clubs and activity groups. Medication lists if applicable, their action plus any side effects;*
- *Read this Survival Guide;*
- *Read [My Care and Treatment Review](#) booklet, for helpful information;*
- *Consider using some [Person-Centred Thinking Tools](#) to aid decision making;*
- *In the days before the review, some people have found it helpful to make two separate 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;*
- *Consider drawing up a list of contacts using the template provided;*
- *If you have notes from a previous C(E)TR, get them ready to take with you;*
- *If you need help with the C(E)TR process, you might want to contact [a support organisation](#) for some support;*
- *Make/check travel arrangements.*

THE C(E)TR PROCESS



ROLE OF ADVOCACY

In the new policy, there's much more focus on the role of Advocacy.

Advocacy is about speaking up and getting support to speak up, to be listened to and have our voices heard. Advocacy is also concerned with making sure that our legal and human rights are respected and upheld. Advocacy should be independent of all other services involved, including the care provider.

People should always be supported to self-advocate wherever possible.

There are different types of advocacy, some types are statutory and others are non-statutory. Statutory advocacy means advocacy that must be made available by law. This includes advocacy for people detained in hospital under a section of the Mental Health Act. In this case, the advocate is called an Independent Mental Health Advocate (IMHA).

Advocacy for families is non-statutory, so it doesn't have to be made available by law. Often the best option for families is peer advocacy if available. A peer advocate could be anyone who shares similar relevant lived experience, who can help you understand the systems and processes you need to work with. Peer advocates are often unpaid due to lack of funding. In many cases, an advocate hasn't been made available, particularly for families.

The person should have regular access to an advocate and have access to information that explains the role in a way in which they can understand. This might be easy read for example or using individual communication methods.

If the person has an independent advocate, they should be invited to the C(E)TR. The panel may speak to them alone or with the person and/or their family. The advocate will aim to support the person to express their views, or if this is not possible, to represent the person's views after taking time getting to know them. If the advocate knows the person well, they may be able to describe the person and their experiences in less clinical ways.

To find out more about the different types of advocacy, how it should work and how it actually works in practice, read the 'Review of Advocacy', published by NDTi in 2023. [Here](#) is a link to the review

BEFORE THE DAY: PREPARING FOR A C(E)TR



PREPARING FOR A C(E)TR

Arrangements for a C(E)TR 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 their own booklet. You might recognise these booklets from the 'My C(E)TR' section earlier in this guide. They have been included here for ease of reference:

[My CTR review](#) and easy read: [My CTR review easy read](#)

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 C(E)TR Planner" will help them prepare and plan for the review and what happens next. Parents can consent for children under the age of 18, who are too young or cognitively unable to understand these processes properly.

[My C\(E\)TR planner](#) and easy read: [My C\(E\)TR planner easy read](#)

This document 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 has been assessed and found to lack 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 must be arranged at the same time and appropriate support provided.

If the person is 16 or over and has said they would like family to attend their C(E)TR, their family will also be contacted by the commissioner (or their representative) ideally at least two weeks before the C(E)TR. The commissioner will ask if they would like to be involved, and if so, whether they would like to attend in person, or if they would prefer to attend remotely by video call (usually through 'Microsoft Teams') or by telephone. They will be sent information explaining the C(E)TR process with details of the names and roles of those on the review panel.

BEFORE THE DAY: PREPARING FOR A C(E)TR



If a best interests decision has been made on behalf of the person because they lack capacity, the family member should ask to see the best interests assessment. Family members should respond to the invitation as soon as possible and should be advised which parts of the day they can attend. If the family members are only available for part of the day, they can let the panel know that, as well as advise on any reasonable adjustments they may need.

If the proposed date is not possible for family, the family should ask if it will be possible to rearrange the C(E)TR to make sure they can attend.

WHAT TO EXPECT - A TYPICAL AGENDA



Care, Education and Treatment Review Sample Agenda

Please note:

- Different areas have different ways of working. This is an idea of what is likely to be included in the agenda.
- Wherever possible for inpatients, at least one member of the C(E)TR panel should try to see where the person is staying. Ideally this should be the commissioner and there is provision in the KLOE process for them to spend time in the environment where they can “Sit and See”.
- The chair of the review is permitted to amend the agenda as they see fit.
- This format is a guide that can be amended to suit the needs of the person, their family and the Multidisciplinary Team.
- At the beginning of each review, panel members should agree their break times, and make any necessary changes to the times suggested below.

BEFORE THE DAY: PREPARING FOR A C(E)TR



Date

Location

Meeting Room: tbc

Hospital Address

C(E)TR Panel

Chair:

Clinical Reviewer:

Expert by Experience:

No.	Agenda Item	Session Attendees	Time
1	<u>Panel and Document Review</u> Welcome, introductions, agenda review and review person's documentation.		9am – 10.30am
Tea Break			10.45am-11am
2	<u>Person</u> Panel to meet with person alone to discuss care, education, and treatment	Panel and Patient	11am – 12pm
Lunch Break: Includes some initial recommendation review (PANEL only)			12pm-1pm
3	<u>Family/Carers</u> Panel to meet with family members to discuss care, education and treatment of this person.	Panel and Family Members/carers	1pm-1.45pm
4	<u>Hospital & External Multi-disciplinary team</u> Panel to meet with MDT to discuss person's care, education, and treatment.	Panel and MDT	1.45pm- 2.45pm
5	<u>Recommendations</u> Panel discussion and recommendations (start filling in KLOE outcome form) Panel Only		2.45pm- 3.15pm
6	<u>Feedback</u> Panel to provide feedback to all attendees and close review.		3.15pm- 3.30pm
7	<u>Planning for next CETR date</u> Panel and MDT to agree next CETR date and whether same panel is preferred.		

BEFORE THE DAY: PREPARING FOR A C(E)TR



PERSON-CENTRED PLANS

A person-centred plan identifies the needs of the person, support currently in place and the lead professionals involved in the person's care (ie Psychiatrist, Psychologist, Occupational Therapist, Speech and Language Therapist, Social Worker, Care-co-ordinator).

The focus is to include the person in their care and for them to be at the centre of future planning and decision-making.

Person-centred plans should also represent who the person is as an individual, their likes and dislikes, how they prefer to communicate, what's important to them, what they want to have happen and anything else that might be important and useful to know.

Many different models have been developed to help people create their own person-centred plan. Some people create videos or audio recordings to capture and present their plan.

Some services and care providers will support people to develop person centred plans and involve their families in this process.

Some families develop person centred plans independently of services and it can be a very useful way of preparing for a C(E)TR and other formal meetings a person may need to attend.

Life-Plans – In some cases, life-plans may be recommended by the panel or requested by the family. Life Planning enables the person and their loved ones to put together a detailed history in a person-centred document to help them have a good quality of life.

Click [here](#) to find out more about Life Planning and what it might involve.

BEFORE THE DAY: PREPARING FOR A C(E)TR



CARER'S MONITORING FORM

The Carer's Monitoring Form was put together by a group of Experts by Experience - family members, whose loved ones have been admitted to a mental health hospital. It was developed by families and commissioners to recognise the crucial role of families in checking the care and treatment their family members receive whilst in hospital.

The aim of the form is to make it easier for families to clearly record and log any concerns to be raised at the C(E)TR. It may also help you to structure any discussions you might have with commissioners about hospital services.

The form provides a list of topics and questions to consider when you visit, attend meetings, or talk with your family member and their support teams. Click the link below to download your copy.

[Carers Monitoring Form](#)

CARER CONTINGENCY PLANNING

If you are an unpaid carer and/or parent for a person on the DSR and their risk is rated at either amber or red, professionals should discuss with you whether a contingency plan should be developed as part of the dynamic support offer. If you agree, you should be supported to create the contingency plan.

Contingency plans set out what needs to happen (necessary actions), in case you are no longer able to provide care, or if you need to decrease the level of care and support you provide. With appropriate consent, relevant information from this plan should be shared with other professionals who may need to put the plan into action.

If you are an unpaid carer, it is important that you know about your right to a referral for a Carer's assessment. Click the link below to find out more about [Carer's assessment](#), how it may support you in your role, with your health and wellbeing, and also help you in finding out what support is available in your local area.

WHAT ARE MY RIGHTS?



This guide is all about helping you know what your rights are, what you and your family are entitled to. This section in particular focusses on your rights as a carer to be involved in the C(E)TR process.

Parents or those with parental responsibility for a child or young person should always be part of the C(E)TR, unless there are safeguarding reasons or other exceptional circumstances. Any such reasons should be recorded.

As a family carer you should be involved in the C(E)TR process, as long as the person (if they are over 16 and have capacity) has given consent for this to happen. The involvement of siblings should also be considered, particularly if they play a significant part in the life of the person, because they can often bring a unique perspective on what's important to and for the person.

At the C(E)TR, there will be an allocated time for you to:

- meet up with the panel
- join the 'Multi-Disciplinary Team' part of the day, if it's felt appropriate
- join for the Feedback session

If the person is under 16 a family member has the right to consent for the C(E)TR to go ahead. Parents have no rights when the child turns 18 unless they have deputyship or lasting power of attorney. Click [here](#) for more information about how, when and why you can apply. If there is no family involvement and the person is found to lack capacity, then a 'Best Interests' assessment will be done by the professionals involved in the person's care.

The organisation "MIND" has helpful information about a person's rights if they are sectioned and detained in hospital under the Mental Health Act 1983.

[About sectioning - MIND](#)

NHS England also has further information about your rights and this can be found here:

[Mental Health Act \(easy read\)](#)

For information about your right to complain, please refer to the section on ['Disagreements and escalation of concerns'](#) on page 44 of this guide.

LOOKING AFTER YOURSELF



'The list of things for parents to be worried about is both broad and endless, encompassing the micro daily issues and the macro global questions.

How can we not be anxious?' This quote is taken from the foreword to the Bringing Us Together 'Anxiety First Aid Toolkit', a resource which offers tools and strategies that we can all use to support our health and wellbeing.

Many parents report feeling particularly anxious about C(E)TRs. We know that making time to look after ourselves can sometimes feel impossible. We also know from experience that we need to see self-care not as a nice to have but as an essential part of our routine if we are to have the inner resources we need to be able to keep going when things get tough.

The 'Anxiety First Aid Toolkit' provides a reminder for us and a structure to support developing our own self-care routines. This includes things like being mindful of taking time for self-care, taking regular breaks, having healthy food and drink, doing some mindfulness, breathing exercises, yoga etc. In C(E)TR meetings, this could include things like taking knitting and art materials in with you, so you have quiet activities to hand to help you and your child keep calm.

Looking after ourselves also includes getting really clear on the people we can turn to for support when we need it. 'Finding our tribe' of people who share important aspects of our lived experience. People who 'get it' can be transformational and make a huge difference to our capacity to keep going in a way which is sustainable and helpful for our families.

It's really important to remember that we need to find what works for us and get into the habit of doing these things on a regular basis. Just because a certain activity works for another person doesn't mean it's right for you. There's a certain amount of trial and error needed to identify our resources. The most important step to take is to make a start, then to be disciplined in developing good habits and to be kind to ourselves, particularly when we make mistakes.

As a starting point, learning about self-compassion and developing this as a practice can really help to develop a supportive mindset, and interrupting that harsh critical self-talk we can all slip into. When we are kind to ourselves, it makes it easier to be kind to others and ultimately to get things done.



The C(E)TR is supposed to be an opportunity for everyone to work together in the best interests of the person - you should expect to hear a range of opinions and views expressed and everyone should be given the opportunity to say what their views are.

Community C(E)TR

If this is a community C(E)TR, 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 cover care, education and treatment and make recommendations about how services can ensure the right community support is established as soon as possible to meet the needs of the person.

Inpatient C(E)TR

If this is an inpatient C(E)TR 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 C(E)TR are independent of the care being provided. They will be able to provide an objective view and challenge the professionals when necessary in a constructive manner.

For the person's family or friends attending the C(E)TR, when they arrive at the hospital, they will probably need to sign in. Depending on the security arrangements in place, they might also be asked to put their purse, wallet, phone or other personal things in a secure locker. This is so they are kept safe. Not all hospitals will have this level of security but for many these are the types of measures in place.

They will then probably be taken through 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. Often the Chair may contact the person's family in advance of the day anyway, to check the best arrangements for them and check if any reasonable adjustments are required.



Before the person and/or their family join the meeting, they may be asked if they would like to speak to the independent member of the panel who has lived experience. This panel member is known as an Expert by Experience (E by E). They are there to listen to the person and their family, and to make sure that their voices are heard.

CONFIDENTIALITY

All written and verbal information will be kept confidential and will not be shared with anyone outside of the meeting. The panel are provided with information about how they need to destroy any personal information they have been given in the course of the review; the method to be used will be discussed and agreed at the end of the review process.

Panel members will have been provided with a code of conduct in the handling of personal information and data that is subject to non-disclosure and requires secure handling.

THE REVIEW

A C(E)TR is an independent review of a person's care. It checks that the person is safe and receiving the right care and treatment for them. It also looks to see if they have good care plans for the future, and that if there are any problems with their health, safety and care, then these get sorted out.

- The person has the right to be treated as an equal in their C(E)TR and to be given all the support they need to take part. They should be fully involved and at the centre of the day.
- A C(E)TR is not just about a person's mental health or how they behave – it is person-centred, so it is about seeing the whole person, their quality of life, their likes and dislikes, their choices, their hopes and their fears.
- The panel will ensure that they have time to speak to the person separately and in private if appropriate.
- If the person is over 16, has capacity to consent and wants their family there, they should also be fully involved.



PHYSICAL HEALTH

The C(E)TR panel will review the physical health needs of the person in the same way their mental health needs are reviewed. This is an essential part of the process to ensure that all physical health needs of the person are being met. The LeDeR report reinforces this priority. LeDeR is a service improvement programme which looks to improve care for autistic people and people with a learning disability. Click here to read the [LeDeR report](#).

The panel will identify any gaps in care as well as the skills and experience of the staff supporting them. In some cases, if the person has specific or complex health needs, the panel members will be matched with relevant experience/knowledge.

[Annual health checks](#) will be asked about for anyone over 14 who has a learning disability alongside any other reported physical health needs.

MEDICATION

Psychiatry is a medical speciality concerned with the diagnosis, treatment and prevention of mental health conditions. Psychiatrists use a range of treatments in their work, including medication. During assessment and treatment, they will sometimes prescribe powerful drugs as a part of a patient's treatment plan.

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, to control challenging behaviour, instead of using other more appropriate treatment options; or for the management of core symptoms of autism.

During the C(E)TR, the independent Clinical Reviewer on the Panel will ask to see the patient's medication chart. They will then explore and gather information to confirm the correct use of medication, and to check that full and regular reviews of medication are taking place. When you meet with the Panel, they will be interested to hear your views about your family member's medication.



If the family have access to the person's medication history, they should take this along as this gives the panel a bigger picture, rather than just looking at the current situation. Families and the C(E)TR panel should expect the prescriber to have documented what the targeted symptoms are for prescribing and families should make sure this happens. These are 8 suggested questions that families and people may wish to ask.

- What is the medication prescribed for and what does it do?
- How do you know it is working?
- How long will it be needed for?
- How do you evaluate the impact or effect of the medication?
- What happens if it does not work or seems to stop working?
- Can it be stopped, and how?
- How will side effects be monitored and how often?
- What other treatments, support or interventions can be used

Source: Griffiths, H. (2020). As a mum, I despaired at how difficult it was to challenge clinicians. Your Autism, Spring 2020, 10-11

The panel want to make sure the patient is not taking medicines that they don't need and to find other ways of helping them. 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.

The issue of the inappropriate use of psychotropic medication has become a significant issue, which NHS England and its partners have aimed to address by the introduction of STOMP and STAMP. The acronym STOMP stands for: Stopping the Over-Medication of People with a Learning Disability, Autism or both.

Please click on these links for further information about Medication and the important role of STOMP and STAMP:

[STOMP / STAMP](#)

[More about STOMP / STAMP](#) and [An online course about STOMP](#)



SETTING THE CONTEXT - YOUR ROLE AS FAMILY MEMBER

The meeting is run by the Chair who will make sure that the day runs as smoothly as possible. The panel will have spent the first part of the meeting studying the notes and patient records, finding out as much about the person and their care as they can.

The C(E)TR is not an inspection of the provider, but the panel will ask 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 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.

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 if the person is an inpatient. The panel will discuss with the care team and the person whether there are more appropriate, effective and safe alternatives to hospital admission.

An inpatient C(E)TR may last most of the working day and discussions may involve something like a dozen people. Neither the person being reviewed nor their family has to attend for the whole meeting. The chair may wish to invite them to join the review soon after the meeting has started but there are no set rules about this as the agenda will vary depending on everyone's availability.

A community C(E)TR 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 care team rather than a hospital. It can also be held where the person is living at the time, if this is felt to be appropriate.

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 give verbal feedback about their findings and recommendations, and clarify who will do what by when.



MEETING SURVIVAL TIPS

- Double check the venue and the start time.
- Remember - the panel and staff are there to help you.
- One of the key aims today is to support people to find solutions and prevent the need for admission to hospital or 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 C(E)TR.
- Stay calm, listen and make notes or jot down questions on your note pad if you wish.
- 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 timescales 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.

FEEDBACK SESSION

On the Agenda a feedback time will be allocated to include feedback to family (assuming that consent has been agreed by the person and that they have capacity) and professionals. This will be an opportunity for family to ask any questions from the day.



KEY QUESTIONS TO ASK

- If I am not happy with the process who can I contact?
- How can we work together to help my child through this?
- Is there an obligation on professionals to deliver their actions agreed in the plan? Is there a route to escalate non-compliance?
- Are there any local support groups for families in our situation?
- Has an EHCP been finalised?
- What therapy is my child receiving?
- (For inpatients) How is communication with the hospital team?
- Has a discharge plan been started? Is there a date?
- Is there a person specification (i.e. what's needed in terms of housing/supported living/residential care/residential school)?
- Have there been any safeguarding incidents? If so, what has happened as a result?
- Is there a Speech and Language Therapist involved?
- Is there an Occupational Therapist involved?
- Has there been a sensory assessment if sensory needs identified?

The [Carers Monitoring form](#) is a useful document to review for questions to ask on the day, particularly pages 5 to 8.

FURTHER INFORMATION

For more information on preparing for the C(E)TR, please refer to page 44 onwards from Care Education and Treatment Reviews (CETRs): Policy and Guidance available on the link below:

[Dynamic Support Register and Care Education and Treatment Review Policy and Guide](#). To open the Easy read version click [here](#).

AFTER THE DAY: FOLLOWING THE C(E)TR



WHAT HAPPENS NEXT

The Chair will now go away and complete the report – the draft report gets sent to the two independent panel members for their comments, and then the Chair can send out the final document.

The person should receive a thank you letter, with information as to how they will be kept informed about progress. Within two weeks of the C(E)TR, if they wish to, the person will be supported to fill in the feedback form in their C(E)TR Planner booklet.

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. Actions will be embedded in the dynamic support register assuming the person consents to be on it.

If there are any concerns that recommendations are not being achieved, the commissioner will escalate these. They will also follow up on any specific quality or safeguarding concerns identified during the review to make sure that they are dealt with appropriately. Concerns should be escalated to the Oversight and Assurance panel in the local Integrated Care Board.

Feedback will be given to the panel members as appropriate.

WHEN SHOULD THE REPORT COME OUT?

Everyone who took part in the meeting should be sent a copy of the finished report within two weeks (10 working days) of the review taking place. 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 the report is not received within two weeks of the C(E)TR, contact the care manager or the commissioner responsible.

AFTER THE DAY: FOLLOWING THE C(E)TR



AFTER A COMMUNITY C(E)TR

If the person is being supported at home in the community, it is vital to ensure the right support is in place to avoid a further crisis situation developing. This was the whole point of the review after all. Working closely and constructively with the care team is vital to help complete the actions and recommendations that have been outlined. If problems emerge, or if something is not right, the person's care coordinator and the provider need to know straight away.

The contact details of the local services and team members supporting the person, including crisis intervention support need to be easily accessible. It's also important to have a Crisis Plan ready that everyone has a copy of.

If the person lives away from the family home, for example in supported living or a residential setting, it is important that families and Care Providers are able to develop a positive working relationship. Depending on the age of the person and their consent if this is required, offering them the benefit of a family's lived experience and knowledge can make a huge difference. It can be a difficult situation because the Care Provider is responsible for the care they provide and sadly, once young people reach the age of 16, the rights of family members diminish substantially. However, a good provider will try their best to work in close partnership with a family.

AFTER AN INPATIENT C(E)TR

The main aims of the C(E)TR are 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 facilitate discharge as soon as possible.

In hospital, ongoing assessment, care and treatment will be governed by day-to-day needs, local policies and procedures. The C(E)TR 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.

As before, if there are any concerns at all, then there needs to be a discussion with the person's hospital team. If problems still persist, then the commissioner should be contacted.

AFTER THE DAY: FOLLOWING THE C(E)TR



DISAGREEMENTS AND ESCALATION OF CONCERNS

Refer to the Policy & Guidance for C(E)TRs. Here is the link:

[Dynamic Support Register and Care Education and Treatment Review Policy and Guide](#)

On Pages 62 & 63 it covers:

- Clinical Disagreements
- Complaints about the C(E)TR process
- Concerns about lack of engagement from all partners
- Responsibility for escalation of concerns

The link below takes you to information about Ask, Listen, Do. This sets out the core principles that organisations are expected to follow to listen and learn, and provides resources to help make things better for people with learning disabilities and/or autism and their families.

[Ask Listen Do](#)

If you have a concern about the care of a person with a learning disability or autism that no one else can answer, you can also email by clicking the link here: england.asklistendo@nhs.net

ASSURANCE AND OVERSIGHT PANELS FOR ACCOUNTABILITY

These panels must meet at least quarterly (more frequently if helpful), and so if there is a concern raised following the C(E)TR then a recommendation could be to take this concern to “the assurance and oversight panel”. This includes any concerns or request for escalation that you might raise as a family member.

The panel would review the C(E)TR report and actions to assure themselves that the person is safe and well, and consider if any further action is needed to support the person’s progress or discharge. Click [HERE](#) to read more on the assurance and oversight panels.

AFTER THE DAY: FOLLOWING THE C(E)TR



FURTHER INFORMATION

It is worth repeating here that the “My Care and Treatment Review” booklet contains lots of helpful information about the whole process, from start to finish.

Links are here:

[My C\(E\)TR planner](#) and easy read: [My C\(E\)TR planner easy read](#)

GROUPS TO CONTACT FOR SUPPORT

Remember, you are not alone! There are some fantastic organisations and groups for you to connect with for support. Here are just a few with websites:

[Parent Carer Forums](#)

<https://nnpccf.org.uk>

[Bringing Us Together](#)

<https://bringingustogether.org.uk>

[Challenging Behaviour Foundation](#)

<https://www.challengingbehaviour.org.uk>

[Contact](#)

<https://contact.org.uk>

[National Autistic Society](#)

<https://www.autism.org.uk>

[\(IPSEA\) Independent Provider of Special Education Advice](#)

<https://www.ipsea.org.uk>

[SENDIASS Home - Kids](#)

<https://www.kids.org.uk/sendiaass-home/>

[Newboldhope](#)

<https://www.newboldhope.com>

You might also want to join groups on Facebook as these can provide a very useful source of support and useful information.



KEY DOCUMENTS

- **Dynamic support register and Care (Education) and Treatment Review policy and guide: plain English version**

<https://www.england.nhs.uk/long-read/dynamic-support-register-and-care-education-and-treatment-review-policy-and-guide-plain-english-version/>

- **Dynamic Support Register (DSR) Care Education and Treatment Review (CETR) young person guides**

<https://www.england.nhs.uk/publication/dsr-cetr-young-person-guides/>

- **Assurance and Oversight Panels**

<https://www.england.nhs.uk/long-read/support-for-the-development-of-integrated-care-system-care-education-and-treatment-review-assurance-and-oversight-panels/>

<https://www.england.nhs.uk/learning-disabilities/care/ctr/care-education-and-treatment-reviews/>

- **Keyworkers**

<https://www.england.nhs.uk/learning-disabilities/care/children-young-people/keyworkers/>

- **Toolkit for C(E)TRs**

Dynamic support register and Care (Education) and Treatment Review policy, code of practice and toolkit

<https://www.england.nhs.uk/learning-disabilities/care/ctr/care-education-and-treatment-reviews/dynamic-support-register-and-care-education-and-treatment-review-policy-code-of-practice-and-toolkit/>

- **Code of Practice**

<https://www.england.nhs.uk/long-read/dynamic-support-registers-and-care-education-and-treatment-review-code-of-practice/>



KEY DOCUMENTS CONTINUED

- **Key Lines of Enquiry guide**

<https://www.england.nhs.uk/wp-content/uploads/2017/03/Care-Education-and-Treatment-Reviews.-About-me.-Easy-read-guide-for-children-and-young-people-in-the-community.pdf>

- **My Care and Treatment Review**

<https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review.pdf>

- **My Care (Education) and Treatment Review Planner**

<https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.england.nhs.uk%2Fwp-content%2Fuploads%2F2017%2F03%2FMy-Care-Education-and-Treatment-Review-Planner.docx&wdOrigin=BROWSELINK>

Easy read versions:

- **My Care and Treatment Review Symbols**

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

- **My Care (Education) and Treatment Review Planner (easy read)**

<https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.england.nhs.uk%2Fwp-content%2Fuploads%2F2017%2F03%2FMy-Care-Education-and-Treatment-Review-Planner-Easy-Read.docx&wdOrigin=BROWSELINK>



KEY DOCUMENTS CONTINUED

- **Care (Education) and Treatment Review document checklist – community**

<https://www.england.nhs.uk/long-read/care-education-and-treatment-review-document-checklist-community/>

- **Care (Education) and Treatment Review document checklist – inpatient**

<https://www.england.nhs.uk/long-read/care-education-and-treatment-review-document-checklist-inpatient/>

- **Children and Young People Keyworker**

<https://www.england.nhs.uk/learning-disabilities/care/children-young-people/keyworkers/>

- **Family Ambassadors**

<https://www.e-lfh.org.uk/programmes/family-ambassadors/>

- **NDTi A Review of Advocacy 2023**

<https://www.ndti.org.uk/resources/research-project/a-review-of-advocacy-october-2023>

- **LeDeR report**

<https://www.kcl.ac.uk/news/2021-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities>

- **DSR and CETR Policy and Guide**

<https://www.england.nhs.uk/wp-content/uploads/2023/01/Dynamic-support-register-and-Care-Education-and-Treatment-Review-policy-and-guide.pdf>



RESOURCES

- **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>

<https://www.nhs.uk/mental-health/social-care-and-your-rights/mental-health-and-the-law/mental-health-act-easy-read/>

- **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>



RESOURCES

- **Disability Rights UK - Links to key documents: Children and Families Act (2014)**

<https://www.disabilityrightsuk.org/links-key-documents-children-and-families-act-2014>

- **Person Centred Plans. Life Planning - Rightful Lives**

<https://rightfullives.net/Stories/Sam.html>

- **Person Centred Thinking Tools**

<https://helensandersonassociates.com/person-centered-thinking-tools/>

- **Oliver McGowan Mandatory Training**

<https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism>

- **STOMP / STAMP**

<https://www.england.nhs.uk/wp-content/uploads/2019/06/stomp-stamp-family-leaflet.pdf>

- **More about STOMP / STAMP**

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

- **Course about STOMP**

<https://www.minded.org.uk/Component/Details/742766>

- **Carers Monitoring Form**

<https://bringingustogether.org.uk/wp-content/uploads/2019/06/carers-monitoring-form-Final.pdf>

- **Ask Listen Do**

<https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

JARGON BUSTER / 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
DSR	Dynamic Support Register
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

JARGON BUSTER / ABBREVIATIONS



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	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

ACKNOWLEDGMENTS



WITH THANKS TO

We are deeply indebted to Ian Penfold, Isabelle Garnett and the wider team of writers, researchers, editors and supporters for their stellar work in creating the original guide in 2017. This update draws extensively on their original work and we hope that this version retains both the spirit and clarity of the original, whilst at the same time, providing an accurate representation of the updated guidance from NHS England.

Thanks are due to the following parents for their invaluable assistance in providing updated content for this guide: Caroline Hunter, Lisa Cookson, Hazel Griffiths, Helen Swift and Nicola Bartzis.

We are very grateful to Yvonne Newbold for her unwavering support and assistance throughout the process and in particular with the final edit. Thanks are also due to Scarlett Milward for checking alignment of content with the updated Policy and Guidance and for her support in finalising the guide.

Finally, special thanks to Katie Clarke and Tony Bamforth from 'Bringing Us Together' for co-ordinating the work and designing this update.

DISCLAIMER



This guide is based upon Policy and Guidance published by NHS England which came into effect as of May 2023.

Bringing Us Together has made every attempt to ensure the accuracy and reliability of the information provided in this Survival Guide. However, the information is provided 'as is', without warranty of any kind. Bringing Us Together does not accept any responsibility or liability for the accuracy, content, completeness, legality, or reliability of the information contained on this website.

No warranties, promises and/or representations of any kind, expressed or implied, are given as to the nature, standard, accuracy or otherwise of the information provided in this Survival Guide nor to the suitability or otherwise of the information to your particular circumstances.

Bringing Us Together shall not be liable for any loss or damage of whatever nature (direct, indirect, consequential, or other) whether arising in contract, tort or otherwise, which may arise as a result of your use of (or inability to use) this Survival Guide, or from your use of (or failure to use) the information in this Survival Guide.

Additional information has been provided indirectly from a wide range of sources in good faith and is believed to be accurate at the time of writing. Referencing this information has been necessary in order to help families understand and make the best use of what is a very complicated process.

This Survival Guide provides links to other websites owned by third parties. The content of such third party sites is not within our control, and we cannot and will not take responsibility for the information or content thereon.

Links to such third party sites are not to be taken as an endorsement by NHS England of the third party site, or any products promoted, offered or sold on the third party site, nor that such sites are free from computer viruses or anything else that has destructive properties. We cannot and do not take responsibility for the collection or use of personal data from any third party site. In addition, we will not accept responsibility for the accuracy of third party advertisements.

To contact Bringing Us Together, please email Katie Clarke on katie@bringingustogether.org.uk or phone 07908 624549

Facebook page: <https://www.facebook.com/bringingustogether>