

This is a repository copy of *S.17 Standard - Practice Guidance: Supporting unpaid carers around hospital leave*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/210200/>

Version: Published Version

Other:

Moran, Nicola Elizabeth orcid.org/0000-0002-6219-0394, Webber, Martin Paul orcid.org/0000-0003-3604-1376, Naughton-Doe, Ruth Jennifer orcid.org/0000-0003-2683-3476 et al. (3 more authors) (2024) *S.17 Standard - Practice Guidance: Supporting unpaid carers around hospital leave*. UNSPECIFIED.

<https://doi.org/10.15124/yao-4jep-kz20>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here:

<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



UNIVERSITY
of York

Supporting unpaid carers around hospital leave

Practice guidance

Nicola Moran
Martin Webber
Ruth Naughton-Doe
Mark Wilberforce
Emma Wakeman
Laura Tucker

June 2023

Contents

- 3** Why should practitioners use this guidance?
- 4** The importance of working with carers
- 5** How the guidance was developed
- 6** What is the guidance for practitioners?
- 7** Item 1: Be knowledgeable about leave and what it means for carers
- 9** Item 2: Identify carers and check what support they need
- 11** Item 3: Support carers as much as possible, give them information about other sources of support, and refer them to available support as needed
- 13** Item 4: Tell carers about 'life on the ward'
- 15** Item 5: Talk to carers about leave and give them written information from the very start of the admission
- 17** Item 6: Involve carers in planning any leave that is happening with them
- 19** Item 7: Discuss any changes to leave with carers as far in advance as possible
- 21** Item 8: Handover care to carers for leave as you would for staff
- 23** Item 9: Get feedback from carers within 24 hours of leave
- 25** Item 10: Support carers when they find leave challenging, and refer them for support as needed
- 27** How does the guidance link with AIMS standards?
- 29** References

Why should practitioners use this guidance?

The guidance was developed to assist practitioners to support unpaid carers (family members, friends) of people detained under the Mental Health Act (1983) before, during and after s.17 leave. It will also be useful in supporting carers of people who are in hospital on a voluntary basis (although the legal rules will not apply). It has benefits for practitioners, carers and patients.

Benefits for practitioners:

- ✓ Positive relationships with carers can minimise stress for practitioners, for example difficult phone calls with carers may decrease when carers feel involved and supported
- ✓ Good relationships and clear communication reduce the likelihood of miscommunication and ensuing frustrations or challenges
- ✓ Feedback from carers informs staff understanding of where the patient is on their recovery journey and patient readiness for discharge
- ✓ The provision of clear guidance for practitioners about how to include and support carers before, during and after leave could increase staff confidence in working with carers around leave
- ✓ Reports and audits for inspection can be streamlined when there is clear guidance to assess against, and organisations can assess their leave processes and learn from the feedback received

Benefits for carers and for patients:

- ✓ Improved outcomes for carers who feel valued and involved in leave
- ✓ Improved experience of leave for carers – research shows that carers' relationships with practitioners are key to their overall experiences (both good and bad) of supporting leave (Wakeman and Moran, 2022)
- ✓ Improved experience of leave for patients, in part by reducing carer anxiety and frustration
- ✓ Consistency for patients and carers across wards, trusts and organisations creates equity and a standard set of expectations

To give the guidance the best chance of making a difference to carers, patients and practitioners, it is important that inpatient ward staff who will be working with carers understand what they need to do in relation to each of the 10 items in the guidance. This is set out on the pages that follow.

The importance of working with carers

An estimated 1.5 million friends and family members provide substantial support to people experiencing mental health problems (Carers Trust, 2020). Sometimes an individual's mental health problems may require them to be detained under the Mental Health Act (MHA) (1983) for assessment and/or treatment, which can mean they need to stay in hospital for a few days, weeks, months or even years at a time. It is important that during such periods the individual remains connected to their family, friends and communities as research has shown that this is key to recovery from mental health problems (Leamy et al., 2011; Sweet et al., 2018; Webber et al., 2019). Maintaining these relationships is also important to carers (Wakeman and Moran, 2022).

People detained under the MHA are often removed from their familiar social support systems through being detained out of area, restricted to infrequent visits from family, or just by being detained in hospital for lengthy periods of time. S.17 MHA (s.17) allows the Responsible Clinician (RC) (or Approved Clinician (AC) – we will use the term Responsible Clinician (RC) throughout) to grant a leave of absence from hospital, which could include an hour in the hospital grounds, visits to local shops, or going home for a few hours or days. This may be supervised so that the individual is accompanied by a family member, partner or friend ('carer') or member of hospital staff, for example to mitigate risk and ensure medication adherence, and/or to test how the patient manages in their home environment to help assess where they are in their recovery journey and their readiness for discharge.

The needs of unpaid carers are perhaps least likely to be considered during mental health hospital admissions, which are becoming increasingly brief (Mental Health Taskforce, 2016). Good practice dictates that planning for discharge should begin at the start of the admission and involve carers (Department of Health, 2008; National Institute for Health and Care Excellence, 2011). Leave from hospital is often provided as a way to assess an individual's readiness for discharge, and the planning of this should also involve carers. However, the Care Quality Commission found that, of those who want friends or family involved, only half of mental health service users report that mental health services include their carers in their care and support planning as much as they would

like (Care Quality Commission, 2019), contrary to policy (Department of Health, 2008) and guidance (National Institute for Health and Care Excellence, 2011). Previous studies have identified that carers feel that professionals do not involve them in decision-making, yet expect them to provide support on discharge (Jankovic et al., 2011; Wilkinson and McAndrew, 2008).

In determining whether s.17 leave might be appropriate, the RC should consider if the individual has access to support from carers and if the carers are willing and able to provide this support. With a rapid turnover in bed occupancy, and moves towards early discharge, there are concerns that carers are not fully involved in decisions about s.17 leave (Wakeman and Moran, 2022).

Under the Care Act 2014 carers' needs must be assessed and appropriate support provided; however, this takes time and is unlikely to include situations in which decisions are made quickly. Most research on carers' needs focuses on carers of older and disabled family members who live with them or close by and who provide often substantial amounts of care; these have found that caring can often have a significant impact on carers' physical health, emotional and mental wellbeing, and finances (Carers UK, 2015; Arksey and Glendinning, 2008). Some carers report mental health issues, most notably depression and emotional stress, as a result of caring (Shah et al., 2010). However, carers of people detained under the MHA are underrepresented in research.

The Triangle of Care (ToC) has been developed to help ensure that mental health services involve carers in planning care for people with mental health problems (Carers Trust, 2013). The ToC provides standards for services to achieve and good practice examples of carer involvement. Over half of NHS Mental Health Trusts in England are part of the ToC Membership Scheme, which is a statement of their intent to be carer inclusive. An evaluation found that the ToC appears to improve engagement with carers, but it requires the support of managers and practitioners to implement fully (Robotham and Billsborough, 2019). However, the ToC does not currently address the specific issues facing carers supporting people on s.17 leave, hence the development of the s.17 Standard and this guidance aimed at supporting unpaid carers around hospital leave.

A recent study undertaken by members of the research team (Wakeman and Moran, 2022) found that carers of people detained under the MHA struggled with anxiety in the lead up to the period of s.17 leave; low mood following periods of leave; stigma from other family members or communities who associated detention with criminality; guilt if/when they struggled to visit, often due to the length of journey and associated cost; and self-sacrifice in relation to taking time off work to care for the patient during

s.17 leave. Notably, the carers in this study received very little support, which may exacerbate the difficulties they faced. Carers reported feeling 'left out' of 'normal' carers' discussions and resources; the emotional toll of s.17 leave; and carers also stated that their relationships with practitioners were key to their overall experiences (both good and bad). There is currently no published research on approaches to improve the support provided to carers during s.17 leave.

How the guidance was developed

Building on the pilot study (Wakeman and Moran, 2022), the research team conducted a larger study entitled 'Section 17 Leave: Supporting unpaid carers', funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR).

During 2021, the research team undertook interviews with carers of people who had been detained under the Mental Health Act (1983) and experienced s.17 leave, and also held workshops and interviews with practitioners and Responsible Clinicians involved with s.17 leave. We sought to understand the issues facing carers around s.17 leave, what they felt worked well and what, if any, additional information or support they felt they needed in relation to s.17 leave. We also sought to understand practitioners' and Responsible Clinicians' views on what they thought worked well for carers around s.17 leave, what they thought could be improved for carers, and the barriers to such improvements for carers. In total we interviewed 14 carers, 15 practitioners and 4 Responsible Clinicians across three study sites.

The three sites that participated in phase one of the study, two NHS Trusts and a private hospital, were selected as they provided a diversity of experiences in urban and rural settings in different locations in England. The locations were selected to provide a range of experiences to feed into the development of the s.17 Leave Standard for Carers. For example, one of the sites was a hospital which provides specialist mental health services for the NHS with many of its in-patients detained under the MHA and coming from across the United Kingdom

for longer stays. The inclusion of this site helped to ensure that the needs of carers of longer-term and out-of-area patients were also considered. Between them, the three sites covered urban areas, small towns and rural areas, market towns, deprived urban and coastal areas, prosperous and deprived rural locations and regional cities.

The s.17 Leave Standard for Carers that was subsequently developed defines the support to be provided to carers before, during and after periods of s.17 leave. It is grounded in what carers felt would help them to feel more involved in communication and decision-making around s.17 leave and also what practitioners and RCs felt would be feasible in practice.

During 2022-23, the guidance was trialled in six NHS Trusts and an additional sample of carers and frontline practitioners took part in interviews or an online survey about their experiences of leave. The 'Challenges and Suggestions' boxes that accompany each item below are based upon the challenges identified during implementation and the suggestions indicated by participants and the research team.

The s.17 Leave Standard for Carers has broad applicability and can also be used with carers of patients who are in hospital voluntarily, hence we refer to 'the guidance' rather than the 's.17 Leave Standard' in this practice guidance.

What is the guidance for practitioners?

The guidance consists of 10 items to help ward staff support and work with carers before, during and after leave:

Background knowledge

1. Be knowledgeable about leave and what it means for carers

When someone is admitted to hospital

2. Identify carers and check what support they need
3. Support carers as much as possible, give them information about other sources of support, and refer them to available support as needed
4. Tell carers about 'life on the ward'
5. Talk to carers about leave and give them written information from the very start of the admission

Planning leave

6. Involve carers in planning any leave that is happening with them
7. Discuss any changes to leave with carers as far in advance as possible

When leave starts

8. Handover care to carers for leave as you would for staff

After leave

9. Get feedback from carers within 24 hours of the leave ending
10. Support carers when they find leave challenging and refer them for support as needed

Record all discussions, actions and feedback with and from carers on the ward records in the most appropriate place

The following pages detail the rationale behind each item and the research on which the guidance is based.

Item 1: Be knowledgeable about leave and what it means for carers



What you need to do

- **Attend regular training around leave which includes the importance of working with carers**
- **Training should be for all ward staff who have contact with carers**

Regular training around leave should include when and how best to involve carers – for the benefit of patients, carers and practitioners alike.

Training should include all ward staff who have contact with carers regardless of their role on the ward. This includes staff such as Health Care Assistants, who often speak with carers but are not always involved in the planning meeting for patients.

Training should include:

- A refresher around s.17 of the Mental Health Act 1983 for those who are detained
- The importance of working with carers
- Trust policy and best practice for working with carers
- Use of the guidance and the rationale behind the items

Carers should be involved in developing and delivering staff training, which should be delivered in person where possible.

Accessing the s.17 leave standard training on the study website (<https://www.york.ac.uk/business-society/research/spsw/supporting-unpaid-carers>) would help you to achieve item 1 (for now!).

Rationale

During the first phase of the study, some carers reported feeling that practitioners saw them as a nuisance. A number of practitioners reported that they/colleagues lacked confidence in speaking with carers due to:

- Concern/fear over saying the wrong thing/saying too much
- Tensions with carers if what practitioners had suggested or assumed did not transpire in practice, especially where staff were not familiar with the patient
- Issues around patient confidentiality
- Staff lacking time and resource to liaise with carers (especially due to staff sickness/vacancies)
- Staff struggling with having difficult conversations with carers



Suggestions by practitioners to help improve their confidence in speaking with carers included:

- Training around 'having difficult conversations' (with carers, patients, staff, etc.)
- A consent whiteboard (listing who the patient has given consent for information to be shared with) accessed only by staff
- Having a designated worker with time allocated to speak with carers
- Filling vacant positions and additional resourcing

A key issue to emerge from the interviews with carers and practitioners was inconsistency: inconsistency of staff member, inconsistency of information, and an inconsistent understanding and application of the 'rules'. Such issues were reported by carers and also by practitioners:

"It depends on which staff team are on as well, because there's not always consistency within what happens on a ward... Yeah, not everybody feels comfortable with that side of things [speaking to carers], so it's about making sure that somebody who is on the team that day is comfortable to take information in, and reassure the family as well." **(Practitioner 10)**

This example underlines the importance of training around leave that includes all staff members in an attempt to bring about consistency in response to carers alongside a shared understanding of the importance of speaking with and involving carers in general but also specifically around leave.

CHALLENGES: Wards can be busy places and staff don't always have the option to take time out for training as often as they would like.

SUGGESTIONS: While protected time for formal training is recommended, wards should also have easily accessible information about best practice with carers and copies of this guidance available around the ward for quick reference and as a reminder. This can include posters, prompt sheets and other easy to access information – like this guide or the shorter summary guidance document!

Item 2: Identify carers and check what support they need

2

What you need to do

- **Identify and contact carers early in the admission to see if they need support for any future planned leave**
- **Remember this is about identifying support needs, rather than providing support**
- **Carer support needs and any concerns about the carer should be discussed within handover and ward round and shared with any other relevant parties**
- **Keep a record of any discussion with carers on your trust recording system so that you can refer back to this later if needed**

Carers can find it difficult to ask for support, so you need to take the lead in talking to them about this.

Checking carers' support needs should happen early in the admission so that relevant support can be provided and/or referrals made. Look at whether the carer seems to be struggling and if there are any issues that might affect leave that need to be addressed.

Concerns about the carer and their support needs should be discussed with the carer to decide a plan where possible and this should be shared with appropriate members of the team/ward as relevant. Make sure to keep records of what has been discussed in case these are needed later.

This item is about assessing carers' support needs and links closely to item three.



Rationale

During phase one of the study, a number of carers spoke about their own difficulties in coming to terms with what had happened to the person they care for and noted how they themselves would have benefited from help, advice and support:

“There’s the shock of somebody going into a psychotic episode or what have you, you know, nothing can prepare you for that at all. And it becomes...it knocks you back, to be honest. In the end, you know, your own mind is struggling... and all sorts of things go through your head and at the bottom of it all, there’s a person you care deeply for, you know, and you just don’t want to see them suffering or in any sort of pain or trouble. And yeah, it’s a whole mixture of emotions... If we’d been offered anything like that [carer support] early on, any help like that early on, then we definitely would have grabbed it with both hands I think.” (Carer 8)

Carer support needs may be identified through, for example: reception meetings early in the admission; informal assessment during visits and phone calls; issues emerging/discussed during ward rounds/team meetings; and if staff escort a patient home for s.17 leave.



CHALLENGES: Ward staff don’t always know who the carers are, especially if they do not come to the ward. Even if they do know, there isn’t always information about these carers easily available and information recorded on the trust systems can be out of date.

SUGGESTIONS: Patients themselves may be the best source of information here – talk to them about the family and friends who support them and they may be able to provide the needed details. If the patient is already under the care of the community team, check with the designated worker in the community who may also be able to provide this information.

Item 3: Support carers as much as possible, give them information about other sources of support, and refer them to available support as needed



What you need to do

- Check whether the carer has already received a carer's assessment. If not, arrange a referral for assessment using your local policies if the carer agrees (this might mean you refer them yourself, or pass this on to someone else to do)
- Hold initial discussions with carers about options for support and liaise with community mental health teams to ensure support is ongoing
- Offer carers information about local carer support services
- Keep a record of any discussion with carers on your trust recording system so that you can refer back to this later if needed

Once you have identified that carers might have support needs, you should also give them information about what support is available and help them to access this if needed.

Carers should be given information about carer support services in the local area, whether these are provided within the trust, or by an organisation in the community. You should also tell them about their right to have a carer's assessment. A carer's assessment is a formal assessment that is done by the local authority or someone acting on their behalf (not by ward staff), which could lead to a formal offer of services for the carer.

In some trusts, carer referrals are done by staff in the community teams, so do speak with the community worker to check who is best placed to do this. On acute wards carer support may not be available until after the patient is discharged and so again this may need to be picked up by the community team. In such cases, ward staff should commence initial discussions around carer support.

You are likely to have some knowledge of the types of difficulties carers might experience around inpatient admission and leave from hospital, and you should talk to carers about this as part of preparing for leave. Keep records of what has been talked about in case this is needed later.

Rationale

In phase one of the study, many carers reported not receiving information about carer support services and/or not being referred for a carer's assessment. Some reported that they would not have wanted this as they would prefer the focus to be on the patient, but others felt that they would benefit or had benefitted from support:

"I'm seeing somebody from the Carers' Centre, about every fortnight I speak to her. That's really helpful... 'cause it does, it's had, yeah, a massive impact on all of us, but especially me, because it's my life that's been changed." (Carer 10)

Of those who clearly stated they would welcome support, many said they would only access support if it was offered as they would not feel comfortable or confident in asking for help:

*"...especially early on, you know, in an illness, people are...it's a traumatic thing and you don't...you're not always thinking straight to ask for the right things or ask the right questions. So I think it is better to come from the professionals who are hopefully, you know, calm and can consider more and offer that help. I'd rather it be offered and us say 'thank you but no thanks', than not... And again, there's this feeling of, you know, am I failing because I'm having to ask for support or ask for help? You know, we've all got that in us I think, that pride of I want to do this myself sort of thing and it isn't always the best way by a long way. And it is that bit easier if it's put to you, 'would this be useful to you?'.**" (Carer 8)***



Carers who had been informed about or offered carer support found some of it lacking:

*"We've had a carer's assessment and we were offered a voucher for a massage, and I thought, well I mean that's nice, but it's not actually going to help me very much."**(Carer 11)***

Rather, carers tended to want more specific help or support, and for many what they really wanted was somebody to listen:

*"[At the carers' centre there is] a person, you know, who will be... who will listen to you, you know, and give you a tissue if you're having a bit of a weep, make your tea and coffee for you if you want it. You know, there's... someone to care, but not be judgemental, or whatever, just, you know, you are there, you need some support, they're going to give it. And if they feel it needs following up on they will follow up on it for you."**(Carer 11)***

CHALLENGES: It can be difficult to find time to talk to carers and complete referrals, especially when wards are busy or working shift patterns mean ward staff are working when carer support services might be closed.

SUGGESTIONS: It's usually best to have discussions to identify carers' needs in person, but there are also other ways you can share information. Have leaflets from local carer support services visible and available on the ward that can easily be shared – you could also include these in carer information packs. Some carer support agencies also have simplified referral processes for professionals that you can do online (if local services don't, you could ask for a process that will work for them and for you).



Item 4: Tell carers about 'life on the ward'

What you need to do

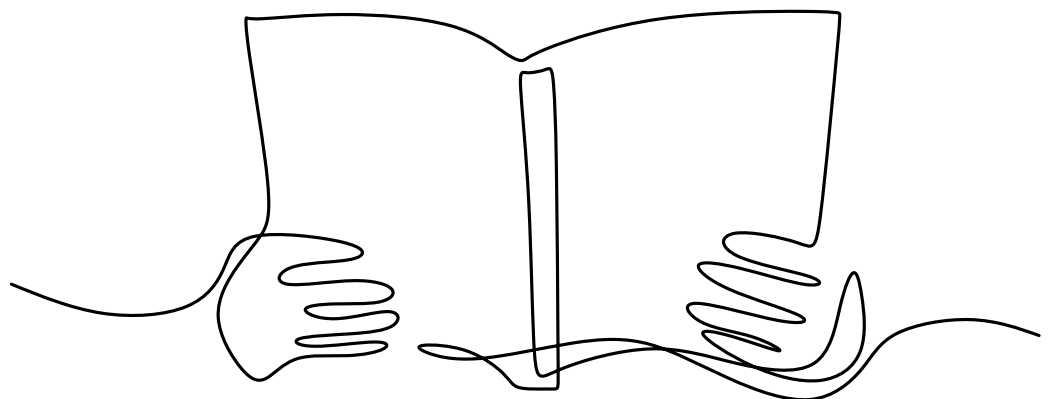
- **Ensure carers have generic information about life on the ward (types and usual times of activities) to help them understand the ward routines so they know the best times to make contact and plan for leave (as well as the times to avoid!)**
- **Share information about how and when carers can be involved in ward meetings as soon as possible in the admission**

Carers need information about life on the ward. This should include basic information such as mealtimes and planned ward rounds but also general information about the usual activities and sessions that the patient may be involved with. You can also use this to indicate when the best times to contact the ward are likely to be.

Information should be general (e.g. "The psychologist visits the ward on Mondays between 2pm and 5pm") rather than about individual patients (e.g. "John is seeing the occupational therapist on Thursdays at 10am"). If a patient does not want to share information about their care with a carer, you can still provide this general information.

Explain to carers about how ward rounds work and when and how they can be involved in this. It is useful to provide this information in writing so that carers can look back at it as they may not remember things they are told at the time of admission to hospital.

Providing carers with information about life on the ward would benefit carers, patients and staff as it would likely reduce the volume of phone calls and visits during meal times or activity sessions, thereby reducing pressure on staff, and may also encourage conversations between patients and carers about the activities or sessions that are available and how the patient is finding them. Further, carers may be able to encourage patients to take part in sessions or activities.



Rationale

Carers raised concerns that leave could interfere with activities and sessions on the ward that may be therapeutic for the person they care for:

“What I don’t want is for my wife to say [to staff] ‘well I can’t see you after one o’clock because I’m going out with [carer]’, and that’s happened and I only found out afterwards when something was happening on the ward which my wife would ordinarily engage with, but she can’t focus on it because she’s more focused on her section 17 leave, you know... I want what’s best for my wife and I don’t want to unwittingly jeopardise that by turning up for section 17 leave to interrupt something of great benefit on the ward say for instance... And if I’d have known that in advance I would have been conscious of the fact that I could have encouraged her to take part in any of those, and I would have been conscious of the fact that I certainly wouldn’t want to distract her by either ringing or turning up during those periods when I thought that if she took part in those she’d get just as much benefit, if not more, than spending time with me.”
(Carer 13)



This provides an example of how carers having more awareness of what was happening on the ward could be beneficial to both the carer and the patient.

Most practitioners anticipated that providing such information to carers may reduce phone calls and planning for leave during core times (meal times, ward rounds, activities or sessions on the ward) and may result in carers encouraging patients to take part in activities – all of which was likely to be of benefit to patients and to carers. However, it was acknowledged that, especially in acute wards, activities may not take place (depending on the acuity of those on the ward) or timings may alter due to incidents and/or energy levels on the ward.

In addition to supporting and encouraging the patient to take part in activities/sessions, carer interviewees and carer members of the study advisory group also stated that having more information about life on the ward helped them to visualise where the person they cared for was and what they were doing, which they found reassuring.

Further, many carers were unaware or had only recently become aware that they could potentially be involved in ward rounds to gain a better understanding of what was happening with the patient and also to have the opportunity to contribute their own thoughts, concerns and experiences, perhaps particularly in relation to leave.

CHALLENGES: Ward staff don’t always have contact with carers from the start of admission and don’t always know how to contact them to send information out.

SUGGESTIONS: Make sure to keep information about life on the ward easily available on the ward so that staff always have this to hand to share with carers. You could also think about displaying this information on posters in visiting rooms or similar places so that carers can see this if they do visit the ward, even if staff are not available.

Item 5: Talk to carers about leave and give them written information from the very start of the admission



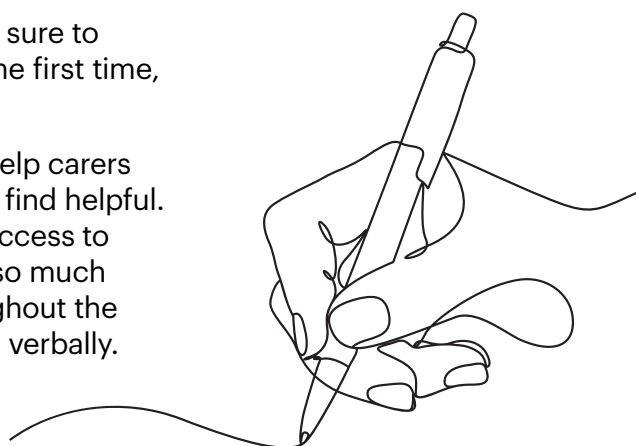
What you need to do

- Talk to carers about the possibility of leave early in the admission, even if it isn't being considered yet
- Hand out a copy of the Carers s.17 leave leaflet at admission and again at the start of leave. Whilst this has been written for carers of patients who are detained, much of the information will also be useful to carers of voluntary patients
- Keep a record of any discussion with carers on your trust recording system so that you can refer back to this later if needed

Give information to carers about leave – what it is and how it works – at the start of the admission. You can talk to carers about leave, so they have a chance to ask any questions, but it is also useful to provide information in writing so that they don't have to rely on their memory.

Conversations can be forgotten and leaflets can get lost. Make sure to provide another copy of the leaflet when leave is planned for the first time, and on the day that leave happens.

A discussion around leave near the start of the admission can help carers to see a potential trajectory and give carers hope that they may find helpful. Providing a written leaflet about leave means that carers have access to information that they can refer to at a later date. When there is so much going on for the carer, around the time of admission and throughout the inpatient stay, it may not be possible to retain information given verbally.



Rationale

Most carers in phase one of the study reported not knowing what s.17 leave was or not knowing that any leave the patient had had was 's.17 leave'. Some carers were unaware that any leave for the patient was even an option:

"We had no idea, nobody ever told us, that he could come home on leave from hospital. It was never mooted... there was so much we didn't know we didn't know. And looking back on it now and I think, oh if only we'd known that and we...you know, we could have done more or been there more or we would have been more involved... At the time we did we got a very helpful phone call, at least I thought it was helpful, but it was information overload. This guy was telling us all this stuff and it was wanging past, you know, I just couldn't take it all in..."
(Carer 11)

Those with experience of caring for somebody during multiple hospital admissions were more likely to have some, though still limited, knowledge of s.17 leave:

"I got the impression it was like a prescription... it's something your doctor prescribes to get you better." (Carer 4)

However, other carers with numerous experiences of leave reported not knowing that that was 's.17 leave' and spoke of the assumptions that staff perhaps made when speaking with such carers and highlighted the gaps in knowledge that carers may have:

"I presume that [hospital] must have assumed that we knew [what s.17 leave was] seeing as [patient had] spent six years somewhere else, but it was a case of we didn't know, and we didn't know we didn't know." (Carer 11)

Almost all carers stated they were not aware of the reasons why the leave had been granted at a particular time or for a specified length of time, and some reported this knowledge would help them to understand if/how the patient was progressing:

"Her leave was going to be extended from four hours daily up to twelve hours or twelve and a half hours daily. And then she moved hospitals and it didn't happen. I don't know why. I've never had it explained to me." (Carer 3)

Most carers also reported being unaware of any 'rules' around leave, for example, whether the patient could have alcohol, whether the carer should follow the patient to the bathroom or outside for a cigarette, whether they could return the patient early from s.17 leave, whether they could ask for the leave to be a little longer (e.g. an extra half hour leave) or where they could/could not take the patient:

"We did have a situation where she was allowed leave, but the leave, she was allowed to come home, and she wasn't allowed to go in any shops. We couldn't stop and go in a shop. But we didn't realise that. We didn't realise that, until I think actually, we had been in one. And then they said, oh no, it's just to go home. So, I think it needs to be really clear." (Carer 10)

Most carers reported that written information that outlined the purpose of s.17 leave and potential options/restrictions would be helpful. Written information alongside verbal information was the preference by carers as this was felt to help carers retain and be able to refer back to the information. This sentiment was echoed by some practitioners and Responsible Clinicians.

CHALLENGES: Ward staff don't always feel confident in their own knowledge of the details of leave, especially when they are not usually involved in planning and arranging this.

SUGGESTIONS: Having the information about leave in writing can be useful for staff as well as for carers. Staff can use the leaflet to answer any questions the carer may have. If staff are still unsure, they should tell carers they will check with the Responsible Clinician for an answer and get back to them later.



Item 6: Involve carers in planning any leave that is happening with them



What you need to do

- **Involve carers in planning any leave which is intended to involve them. Where patients organise their own leave, as set out in the patient plan, consider if the carer has been involved and support the patient to include them as needed**
- **Explain to carers why the patient is ready for leave**
- **Make sure that any plans consider carers' other commitments, like work and childcare**
- **Do not spring leave on the carer – if they are involved in supporting the leave, they should also be involved in planning it**
- **Discuss with the carer ideas for where to go on the leave, especially if the carer does not know the local area**
- **Keep a record of any discussion with carers on your trust recording system**

Leave with a carer needs to be planned with the carer. This means that the timing of the leave should be agreed with the carer to fit around other commitments they have such as work or childcare. Carers should be given the chance to speak in private about the plans, away from the patient, so that they don't feel under pressure to agree if they have any concerns. Staff should also use this time to explain why leave is currently seen as appropriate and confirm that risk assessments have been undertaken, especially where carers are concerned that patients are expressing delusional thoughts, for example.

You are likely to have spent more time with the patient than the carer has during the admission. You are also likely to know the area local to the hospital. You are therefore in a good position to help carers plan the leave, including suggestions on where to go and what to do, providing options suitable for the weather, how the patient is, and how long the leave is for. This could incorporate suggestions for the types of things that the patient has been expressing an interest in, places other patients have enjoyed going to, and places that are relatively quiet etc. If the carer is not familiar with the area staff could provide a list of local activities, quiet places to go, hotels and so on. Such a list would need to be reviewed and updated regularly. Make sure to record these discussions with carers in the ward records so that they can be referred back to later if needed.

Rationale

Carers discussed a range of difficulties they had encountered around s.17 leave, primarily around the relative lack of notice they received about when leave would happen. Some carers reported being contacted and asked if they could support s.17 leave



that day and while some were able and willing to do this, others were not, especially if they had work or childcare or other commitments. Indeed, a number of carers felt that their other commitments were not accounted for and felt angry or frustrated at being expected to drop/change plans/their other commitments at little notice to accommodate the leave.

Some carers reported feeling pressured into supporting s.17 leave at a particular time and being made to feel guilty if they refused. For example, one carer reported turning up at the hospital for a visit and being told (in front of the patient) that they could take the patient home or out on leave there and then:

“When they’re saying it in front of [patient], it’s quite difficult to say, ‘well actually, I’m not sure that’s the best idea’... But then of course, I felt like the bad guy... If they’d spoken to me beforehand I might have said then, ‘well, you know, maybe, a staff member coming, I don’t know this area at all, I don’t know the grounds, I don’t know where we can go.’” (Carer 10)

The carer went on to report that a serious incident had occurred during that s.17 leave which affected the carer in terms of both the trauma of the incident and also the self-blame of not speaking up against the leave when it was suggested to her in front of the patient.

A number of carers expressed shock and frustration that the patient could have leave very shortly after admission and/or whilst they were still expressing delusional thoughts. Further explanation as to why leave was thought appropriate at that time may have helped.

A further issue raised by carers was not knowing where to go or what to do during the leave, especially if the hospital was not close to home and the area was unfamiliar. A list of suggestions about where to go on the leave was suggested by a number of carers and reported to be a good idea by most practitioners:

“And advice about the local area because if you don’t live in the area you don’t know where to go... and that just on top of the emotional strain and the physical effort of going, and all the rest of it, it just adds one more layer of difficulty that’s unnecessary because it wouldn’t take someone that long to comprise a little booklet.” (Carer 11)

Such planning could help to alleviate some of the challenges facing carers around s.17 leave.

CHALLENGES: Ward staff don’t always work locally to where they live and aren’t always familiar with what might be available. Carers aren’t always available to attend ward round meetings where leave is planned.

SUGGESTIONS: Keep a list of local options available on the ward for staff and carers to refer to when leave is planned. Talking to patients and carers about where they have visited during leave will help to give ideas for suggestions for future visits. When decisions are being made in ward rounds, make sure that the details are not finalised; agree a provisional plan for leave and be explicit that the details will be finalised once the ward has spoken with the carers – don’t commit carers to things they may not be able to do.



Item 7: Discuss any changes to leave with carers as far in advance as possible



What you need to do

- If you become aware that planned leave with a carer needs to change, contact the carer as soon as possible to talk about this, or support the patient to do so if appropriate
- Do not finalise any changes before you have spoken to the carer. This may include changes to:
 - Date/duration of leave
 - Whether the leave is also escorted by staff
 - Where the patient may/may not go

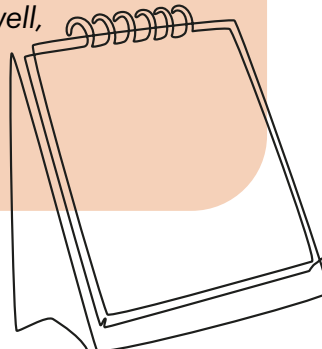
Occasionally plans for leave need to change at short notice. This should only happen when there is no other option. Even with short notice, changes should always be discussed and agreed with the carer before they are finalised.

Be clear about any specific requirements around the leave, for example places where the patient cannot go on the leave.

Rationale

The study highlighted examples of last-minute changes to s.17 leave arrangements that had caused quite considerable distress to the carer and potentially also to the patient:

"One of the nurses had suggested planning some home leave, and they said, to start with one hour at home, with staff present, and that staff would bring him home, and then take him back to the Unit... I was really nervous about it because he was still having delusional thoughts and he could be quite aggressive over the phone. So we were nervous about him coming... But the staff brought him and just dropped him off. And then came back for him an hour later. So, that was a real shock, I really, I thought that was really bad, because we were really nervous and [he] had been in for about 10 weeks, it was a long time, and I think he was overwhelmed as well, with it, so, I thought that was really bad that they didn't do what they said they were going to do on the day. I was scared, I didn't know what was going to happen." (Carer 14)



In the example above, whilst it may have been unavoidable that staff were no longer able to stay at the house to support the leave, the carer should have been given notice of this change so that they could either prepare themselves for this change, discuss their concerns with ward staff and know what to do or who to call if the leave wasn't going well, or have the opportunity to refuse this revised leave arrangement and reschedule escorted leave for another occasion.

Other examples of s.17 leave being changed or challenged at the start of the leave included a dispute over the hospital boundary where the Responsible Clinician had informed the carer that the patient could go into the hospital car park to see the family dog but the nurse had insisted that the hospital boundary was the external door to the hospital.

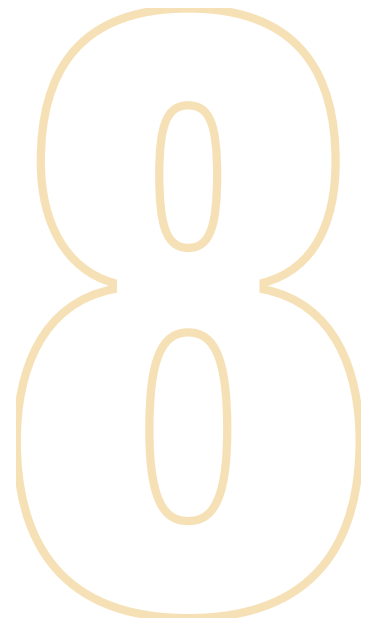
"So, according to the consultant, the boundary was the border round the car park; according to this staff nurse, the border was the door... [so we were] waiting for ages for somebody to sign this blinking form, to go out in a locked car park, it was very frustrating and [the patient] got really cross." (Carer 10)

Ensuring clarity about the leave prior to the leave taking place can reduce such upset, confusion and change.

CHALLENGES: It can be difficult to get in touch with carers at short notice as they are not always available to discuss changes. If leave is changed, it may be due to a crisis on the ward and this makes it hard to prioritise contacting carers.

SUGGESTIONS: Build a plan for last minute changes into your planning for leave with carers. Ask the carer about the best way to get in touch at short notice if leave needs to change. Make sure they know that changes to leave are always a possibility and provide examples of when this may happen – this will keep their expectations realistic. Make sure this plan is clearly recorded and shared in staff handovers so that whichever staff are working on the day of leave can follow it.

Item 8: Handover care to carers for leave as you would for staff



What you need to do

- At the start of the leave, make sure carers have all the information they need about the patient – how they currently are, what is needed for care and medication – and who to call if they have concerns during the leave
- Hand out another copy of the Carers s.17 leave leaflet
- Explain that carers should contact the ward if they have any concerns during or after the leave, and what to do in an emergency situation
- Be clear about any specific requirements or expectations for the leave, such as timings and restrictions
- Keep a record of the handover with carers on your trust recording system so that you can refer back to this later if needed

When care of the patient taking s.17 leave is handed over to the carer, there needs to be a handover of information. During hospital admissions, staff usually have more up-to-date information about a patient than carers do and it is important to make sure that this information is passed on when leave takes place with the carer. Tell carers about how the patient is doing, any medication needs during the leave and what to do if there are concerns. Stress to the carer that it is better they contact the ward early with any concerns rather than wait for a concern to escalate. If a situation does escalate, be sure the carer knows when they should call the ward and when they should call the emergency services. You should also confirm when the patient is expected to be back on the ward and highlight any restrictions on what can be done during leave – do not assume carers already know this.

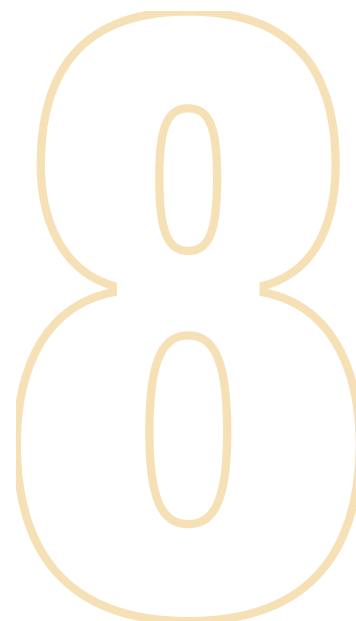
Carers should have had a copy of the Carers' s.17 leave leaflet already, but it would be good practice to give them another copy at the start of the leave. Make sure to record details of the handover on the ward records in case you need to refer to these later.

Rationale

During phase one of the study, carers reported wanting more information about how to be with the patient during s.17 leave – for example, whether to follow them to the toilet or what to do if there was a potentially serious incident:



"You want to know something about what the expectations are of you. You know, things like if she gets up and goes to the toilet, are you supposed to go with her or can she go on her own... all those logistical things that sometimes you're like, I don't know what we're supposed to be doing here. So, you know, what is she allowed to do and what is she not. And what are we supposed to be doing to make sure she does the things she's supposed to do. So how far...you know, like, if she's going out to smoke a cigarette, have I got to go outside with her and stand with her while she smokes her cigarette, or can she go out on her own... [Also, following a serious incident during the leave] it was all very, very difficult but nobody had told us what we should do in that situation. There had been no discussion about whether we should take her to A&E or whether we should phone [the ward] and stuff like that... And maybe they assumed that we knew those things. And we didn't ask, so maybe we assumed that we knew all that we needed to know." **(Carer 12)**



Most carers reported that a quick chat with staff about how the patient was getting on would be helpful, as would a written information sheet about what to do if there were incidents during the leave:

"I think some kind of small, confidential chat before you go out would probably be, so you've got a chance to say, 'well actually, you know, I'm a bit concerned'. If you've got any concerns, you can say, 'I'm a bit worried about this, that and the other, if she does this, what shall I do?'" **(Carer 10)**

Some carers were aware they could phone the ward if any issues arose during the leave but were concerned about jeopardising the patient's treatment and hospital stay or potential discharge.

A small number of practitioners reported discussing care or medication requirements, options of what to do on the leave, and what to do if carers had concerns, with the carers prior to the leave. However, others noted that there was not always sufficient staffing or resource to do this comprehensively and some assumed that carers would already know such information. Most practitioners agreed that there was room for improvement:

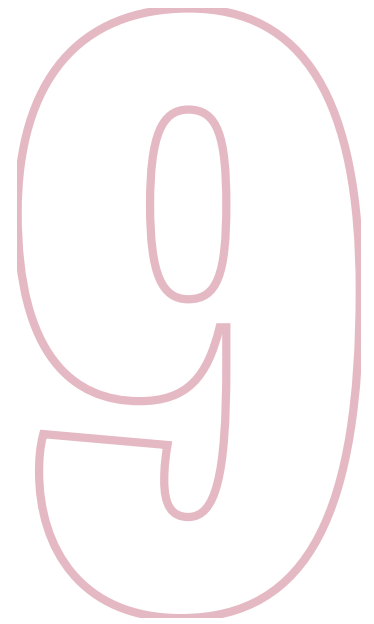
"If carers aren't fully aware of what to do if there is an incident or concern during the leave they may end up getting the police involved which can add to the trauma for the patient... [So it would be] better for the ward to be alerted and they can go and pick up the patient. So written information would be helpful. Something for carers to immediately refer to if there was a situation." **(Practitioner 4)**

Thus immediately prior to the start of the leave carers should be given written information about how the patient is, any medication or care requirements and who to contact if they have concerns during the leave.

CHALLENGES: Carers do not always come on to the ward at the start of leave; sometimes patients meet them outside the hospital, or travel home alone and meet them there.

SUGGESTIONS: Build the handover into your planning for leave with carers. Check how and where the carer will be meeting the patient and, if need be, plan a telephone call for earlier in the day to complete the handover. It can be useful to have a named person for this, so that you know it won't be missed.

Item 9: Get feedback from carers within 24 hours of leave



What you need to do

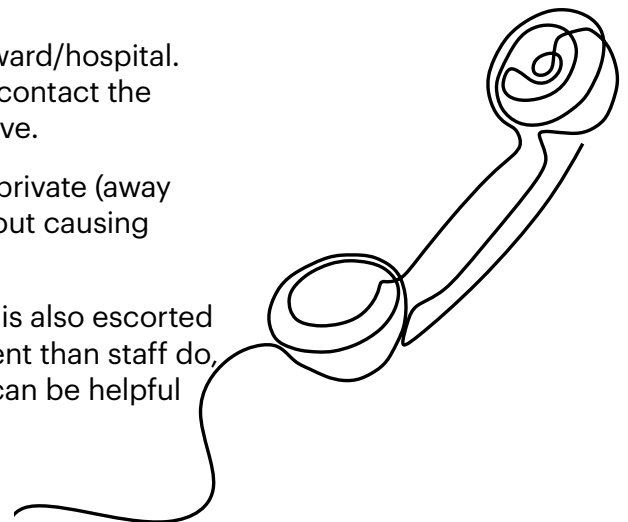
- Ask carers for feedback following leave with the carer, ideally in person when the patient comes back to the ward
- If this is not possible, a named staff member should call the carer within 24 hours
- Take the lead in asking carers for feedback (don't wait for them to offer it)
- Give carers a private space to share their feedback (away from the patient)
- Ask carers for feedback even where the leave is also escorted by a staff member
- Record feedback in the patient notes to inform patient care and future practice

Carer feedback is important. It provides valuable information about how the patient managed during the leave which can inform care and treatment decisions.

Ask for feedback when the carer returns the patient to the ward/hospital. Where this is not possible, identify someone in the team to contact the carer to seek feedback within 24 hours of the end of the leave.

Carers should have the opportunity to provide feedback in private (away from the patient) so that they can be open and honest without causing distress and upset to the patient.

It is useful to ask carers for their feedback even when leave is also escorted by staff. Carers usually have a better knowledge of the patient than staff do, and they may notice things which your team hasn't, which can be helpful for care and treatment decisions moving forward.



Rationale

Most carers and practitioners recognised the value in carer feedback, both for the carer who may need the opportunity to effectively debrief on the visit and to feel that their views and experience are valued by staff and also for the patient as the carer would be well placed to comment on how the patient's behaviour during the leave compared to their actions/behaviour prior to admission and/or their usual state:

"We always want that feedback, because we can't...it's really hard for us to see the whole picture, so we see the snapshot of when they're with us on the ward, but we need that collateral from families after leave to see how things are progressing." **(Practitioner 6)**

Carers wanted to feedback on how the leave had gone and they wanted the opportunity to do so in private (away from the patient) if necessary. Carers

felt they had important experiences and viewpoints to share and that their feedback should inform decision-making. Most carers acknowledged that feedback could not always be given in person at the point of returning the patient to the ward/hospital as the staff may not have capacity in that moment. However, they wanted staff to contact them to find out how the leave had gone.

Some carers did not feel comfortable or confident in contacting the ward to volunteer this information – some were nervous, timid or had had previous bad experiences; others felt the staff did not want or value their input. Almost all carer participants reported that the onus should be on staff to ask carers for feedback about how the leave had gone and if that was not possible to do in person at the end of the s.17 leave then staff should phone carers to directly enquire about the leave.

Almost all practitioners and Responsible Clinicians asserted that carers were aware they could phone the ward at any time to provide feedback and that where possible – where staffing and the absence of critical incidents on the ward permitted – that staff should ask carers for feedback immediately following each episode of s.17 leave as the patient was returned to the ward.

One RC explained how carer feedback was invaluable to their decision-making:

“That’s really helpful to me being in charge of their overall care, to get that feedback... Because there is evidence to suggest that hospital isn’t always the right place. Certainly, when patients get to a stage of recovery it can become detrimental... so you’re trying to get them back into the home environment. So, getting that feedback is crucial really... It just informs my decision making really, it makes it a lot easier for me to understand what level of recovery somebody’s at.” (RC 2)

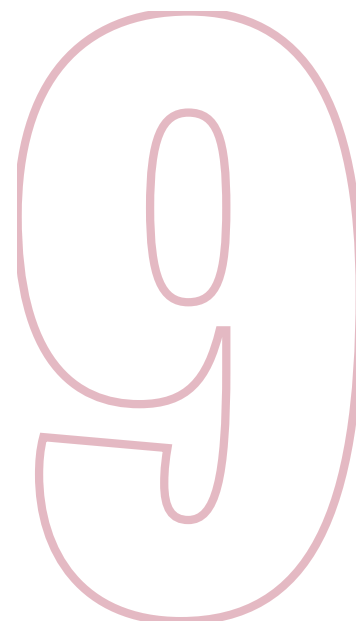
The challenge however was staff capacity to spend time with carers to obtain feedback:

“I think it’s like everything within this job, it’s time limited... we certainly sometimes don’t have time to spend an hour talking to somebody in reception, whilst we’ve got two staff on the ward, and we’ve got 15 patients on.” (Practitioner 13)

Almost all participants acknowledged the potential benefits of privacy in providing feedback in terms of protecting the carer-patient relationship and trust within that relationship and enabling carers to be more open in giving feedback that could assist staff in supporting the patient with their recovery. The majority of staff argued that there should be an opportunity for carers to give feedback in private.

CHALLENGES: Staff don’t always see carers when they come back to the ward, and it can be difficult to get hold of them afterwards, especially if both carers and staff are busy.

SUGGESTIONS: Build this into your planning for leave with carers. You can agree a plan with carers for contact when you know they will be available and also plan this for a time when it is most likely to be quiet on the ward. It can be useful to name a member of staff to do this so that it is someone’s responsibility to make sure it happens. Make sure this plan is clearly recorded and communicated in staff handovers so that whichever staff are working on the day of leave can follow it.



Item 10: Support carers when they find leave challenging, and refer them for support as needed

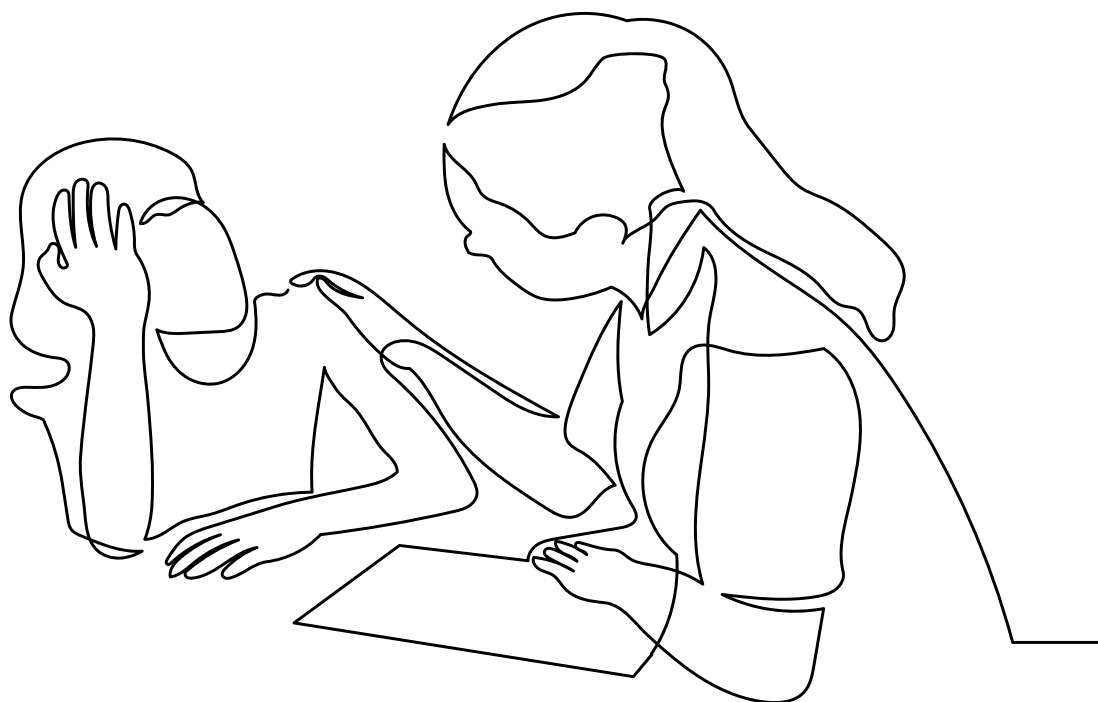
10

What you need to do

- **Speak to carers when leave has been difficult (regardless of when you find out about this) and check if they need any support**
- **Offer the opportunity to debrief with an appropriate member of the ward team, or a referral to carer support services (even if the carer has previously refused this)**
- **Keep a record of the issue on your trust recording system so that you can refer back to this later if needed**

Leave does not always go smoothly and it can be difficult and upsetting for carers, even the most experienced ones. It is important to make sure that staff are aware of any issues as this might be relevant for the patient's care. Carers may also need support to help them to understand and deal with what happened and how to make sure this does not happen in the future.

Ward staff have a lot of relevant experience that can help with this and it can be helpful to speak with a carer directly. Staff can also use this time to identify where carers might need some extra support and arrange referrals to local support services that can offer this.



Rationale

Carers spoke of the toll on their own MH when they felt invisible or unsupported by services following a traumatic incident around the leave. For example, following a particularly traumatic incident during a period of s.17 leave, one carer said:

"I'm sure that I have been more affected by what happened because I didn't at the time get a chance to talk about how I felt at the time, with staff... And I think often the unit sort of, they take off the [patient] and they forget that actually, yeah, there's the poor old person who's been out with them, has just suffered potentially a quite upsetting experience... somebody should have come in and said, 'what happened, and what went wrong?' But they didn't. They gave me a cup of tea, sat with me for a bit, and then went, and then I saw [patient] again before I left, and then that was it. There was no debrief as it were, about what went wrong, and how I felt about it, apart from obviously upset, 'cause I was crying quite a lot. But there was no opportunity to talk about how I felt at all... [I wanted] to be given that opportunity to speak to somebody about how it went... I think there needs to be, especially if there's a traumatic, if something's gone wrong, there definitely needs to be a lot more support for the poor carer." **(Carer 10)**

A different carer, who had also been distressed by an incident during s.17 leave, made a comparison to the regular support offered to staff and argued that carers also require some form of emotional support:

"Staff get clinical supervision. And we are caring for these people, we should have something." **(Carer 12)**

Support needs to be offered to carers following any difficulties during the leave.

CHALLENGES: There is not always somebody available to speak to carers when an issue is identified, depending on what else is happening on the ward.

SUGGESTIONS: While it is best to speak with carers at the time if possible, you can also arrange to speak with them later, in person or by telephone. Make sure that the carer understands why there is a delay and agree when you will speak to them. Tell them who will be contacting them and who they should get in touch with if the contact is missed for some reason.

How does the guidance link with AIMS standards?

The guidance does not conflict with the AIMS standards set out by the Royal College of Psychiatrists in their 'Standards for Acute Inpatient Services for Working Age Adults' (Penfold et al., 2019). Of the 204 items in the AIMS standards, 18 related closely to working with carers. Of these, 15 can be mapped on to the guidance (although two refer to information being shared with the patient whilst we argue this information should also be shared with the carer as appropriate) and three do not map onto the guidance as they do not overlap with leave.

AIMS standard	AIMS item	Link to guidance
Admission and assessment	7. The patient's main carer is identified and contact details are recorded.	Item 2.
Care planning and treatment	31. The team and patient jointly develop a leave plan, which is shared with the patient, that includes: <ul style="list-style-type: none"> a risk assessment and risk management plan that includes an explanation of what to do if problems arise on leave; conditions of the leave; contact details of the ward/unit and crisis numbers. 	Items 5, 6 and 7. However, AIMS refer to the leave plan being developed and shared with the patient, while we suggest also developing and sharing this with the carer when leave is with the carer.
	32. Staff agree leave plans with the patient's carer where appropriate, allowing carers sufficient time to prepare.	Item 6.
	45. Every patient has a 7-day personalised therapeutic/recreational timetable of activities to promote social inclusion, which the team encourages them to engage with.	Item 4. However, AIMS refer to the 'timetable' being shared with the patient, while we suggest that similar information is given to the carer.
Patient and carer experience	91. The team provides each carer with accessible carer's information. Guidance: Information is provided verbally and in writing (e.g. carer's pack). This includes the names and contact details of key staff members on the unit and who to contact in an emergency. It also includes other local sources of advice and support such as local carers' groups, carers' workshops and relevant charities.	Items 3, 5 and 8.
	92. Carers feel supported by the ward staff members.	Item 1.
	93. The ward/unit has a designated staff member dedicated to carer support (carer lead).	This is not included in the guidance as it is far broader than leave.
	94. Carers have access to a carer support network or group. This could be provided by the ward/unit or the team could signpost carers to an existing network.	Item 3.
	95. Carers are able to access regular group meetings that have a psychoeducational focus.	Not included, but potentially links to item 3.
	96. Carers (with patient consent) are involved in discussions and decisions about the patient's care, treatment and discharge planning.	Item 6.
	97. Carers are supported to access a statutory carers' assessment, provided by an appropriate agency.	Item 3.
	98. Carers are offered individual time with staff members, within 48 hours of the patient's admission to discuss concerns, family history and their own needs.	Items 2, 3, 5 and 6.
	99. Carers have access to a specialised pharmacist and/or pharmacy technician to discuss medications.	This is not included in the guidance.
	101. The service asks patients and carers for their feedback about their experiences of using the service and this is used to improve the service.	Item 9.

AIMS standard	AIMS item	Link to guidance
Staffing and training	138. Patients and carers are involved in delivering and developing staff training face-to-face.	Item 1.
	139. Staff training includes: The use of legal frameworks, such as the Mental Health Act (or equivalent) and the Mental Capacity Act (or equivalent).	Item 1.
	145. Carer awareness, family inclusive practice and social systems, including carers' rights in relation to confidentiality.	Item 1.
Governance	191. Staff members, patients and carers who are affected by a serious incident including control and restraint and rapid tranquilisation are offered post-incident support.	Item 10 (for carers).

For further details of the AIMS standards, see the *Royal College of Psychiatrists' Standards for Acute Inpatient Services for Working Age Adults, 7th edition, 2019.*

References

- Arksey, H. and Glendinning, C. (2008) Combining Work and Care: Carers' Decision-making in the Context of Competing Policy Pressures. *Social Policy & Administration*, 42(1), 1-18.
- Care Quality Commission. (2019) *2019 Community Mental Health Survey*. Statistical Release. London: CQC.
- Carers Trust. (2013) *The Triangle of Care: Carers Included: A Guide to Best Practice in Mental Health Care in England*. London: Carers Trust.
- Carers Trust. (2020) *Key facts about carers and the people they care for*. <https://carers.org/key-facts-about-carers-and-people-they-care>. Accessed on 27.1.2020.
- Carers UK. (2015) *State of Caring 2015*. London: Carers UK.
- Department of Health. (2008) *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance*. London: Department of Health.
- Jankovic, J., Yeeles, K., Katsakou, C., Amos, T., Morriss, R., Rose, D., Nicol, P., McCabe, R. and Priebe, S. (2011) Family caregivers' experiences of involuntary psychiatric hospital admissions of their relatives – A qualitative study. *PLoS ONE*, 6(10), e25425.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J. and Slade, M. (2011) Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, 199(6), 445-452.
- Mental Health Taskforce. (2016) *The Five Year Forward View for Mental Health*. London: NHS England.
- National Institute for Health and Care Excellence. (2011) *Service user experience in adult mental health services: improving the experience of care for people using adult NHS mental health services*. *Clinical Guideline 136*. London: National Institute for Health and Care Excellence.
- Penfold, N., Nugent, A., Clarke, H. and Colwill, A. (Eds) (2019) *Standards for Acute Inpatient Services for Working Age Adults 7th Edition* Royal College of Psychiatrists Quality Network for Inpatient Working Age Mental Health Services (QNWA) CCQI 309. London: Royal College of Psychiatrists Centre for Quality Improvement.
- Robotham, D. and Billsborough, J. (2019) *Triangle of Care – Lessons Learned from Implementation*. London: McPin Foundation.
- Shah, A.J., Wadoo, O. and Latoo, J. (2010) Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners*, 3(3), a327.
- Sweet, D., Byng, R., Webber, M., Enki, D.G., Porter, I., Larsen, J., Huxley, P. and Pinfold, V. (2018) Personal well-being networks, social capital and severe mental illness: exploratory study. *The British Journal of Psychiatry*, 212(5), 308-317.
- Wakeman, E. and Moran, N. (2022) The Missing Voices: Carers' experiences of Section 17 leave (Mental Health Act 1983) in England. *Practice: Social Work in Action*, 34(2), 133-147. DOI: [10.1080/09503153.2021.1928620](https://doi.org/10.1080/09503153.2021.1928620)
- Webber, M., Morris, D., Howarth, S., Fendt-Newlin, M., Treacy, S. and McCrone, P. (2019) Effect of the Connecting People Intervention on Social Capital: A Pilot Study. *Research on Social Work Practice*, 29(5), 483-494.
- Wilkinson, C. and McAndrew, S. (2008) 'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International Journal of Mental Health Nursing*, 17(6), 392-401.

This guidance has been produced from research led by the University of York, undertaken with carers, practitioners and Approved/Responsible Clinicians at Humber Teaching NHS Foundation Trust, Tees Esk and Wear Valleys NHS Foundation Trust, St Andrew's Healthcare Northampton, Leeds and York Partnership NHS Foundation Trust, South West Yorkshire Partnership NHS Foundation Trust, North East London NHS Foundation Trust, and South West London and St George's Mental Health NHS Trust.

The guidance has been developed from independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the organisations that took part in the research, the NIHR SSCR, the NIHR or the Department of Health and Social Care.

