



UNDERSTANDING AND MANAGING AGITATION

For people who experience agitation, their carers, friends and family





CONTENT

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Written by Chiara Samele on behalf of GAMIAN-Europe & EUFAMI

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1. INTRODUCTION

Agitation is a common experience for people diagnosed with bipolar disorder, schizophrenia and dementia. Agitation is also experienced by people with depression and anxiety disorders.

When agitation takes place it can escalate very quickly and if severe may require a hospital admission which can all be very distressing. Early recognition of signs and symptoms and acting quickly are crucial to avoiding this situation. Many people who experience agitation are able to recognise their symptoms/ episodes and should be empowered to anticipate and manage, with the support of their carers and clinicians their symptoms and avoid admission to hospital as far as possible.

This guide has been produced as part of a collaboration between GAMIAN-Europe and EUFAMI and aims to provide information for people who experience agitation and those close to them. It includes a description of what agitation is, how it can be managed and what available treatments can help. It is written from the perspective of people with lived experience of agitation and carers, and also draws on existing research.

1.1 WHAT IS AGITATION AND HOW COMMON IS IT?

Agitation is described as:

**a behavioural syndrome
or set of symptoms
or behaviours.**

It is not an illness in its own right but usually a symptom of a mood disorder or other medical condition. It is important therefore that a clinician or therapist is able to recognise agitation as part of or in addition to an underlying condition.

The causes of agitation are varied and can be the result of drug use, a traumatic or distressing situation or an underlying physical or mental illness. When someone with schizophrenia or bipolar disorder becomes emotionally distressed agitation can be expressed as inner tension, restlessness, nervousness, uneasiness, fidgety, excitement, anxiety, uncooperativeness, irritability, verbal or physical aggression (Roberts et al, 2018; Sachs, 2006). Agitation can go from anxiety to high anxiety, or even to violence and/or aggression. There is no agreed or precise definition of acute agitation (Cummings et al, 2015), but one description is:



When people experience an episode of agitation they may feel noticeably more tense, restless, wound up, uneasy or short-tempered than usual. Some people talk a lot more than they would usually or find it difficult to keep still. Sometimes agitation leads to violent or aggressive behaviour but this isn't always the case. An episode of agitation will subside after a while

(Blanthorn Hazell et al, 2018).



However, agreement among experts as to what agitation is and what it means is still required, especially across different languages and cultures. For example, when does restlessness become a problem and for whom, and how does body language indicate symptoms of agitation if the person is not communicative? An episode of agitation may also be linked to anxiety which could be linked to depression.

Figure 1
IDENTIFYING SYMPTOMS OF AGITATION



The prevalence of agitation is very high and estimates range from 4.6% to 52% in ward or emergency settings (San et al, 2016; Boudreaux et al, 2009; Mellesdal, 2003). There are very limited studies for the prevalence of agitation outside the hospital setting, but one European Survey found on average patients can experience approximately three mild to moderate episodes of agitation in one month (Roberts et al. 2018).

1.2 WHY IS AGITATION IMPORTANT TO UNDERSTAND?

Agitation can be very distressing for the people who experience it and for those who are close to them. It can negatively impact on people's day to day lives, their relationships, health and functioning at school, work or at home.

If agitation becomes severe a person could require an admission to a psychiatric hospital. Patients in psychiatric wards who have an episode of severe agitation have been found to have longer length of stay, are more likely to be readmitted to hospital and be given more medication (Rubio-Valera, et al., 2015). In addition, the use of restraint, seclusion, containment and other coercive methods are often used to manage severe episodes of agitation in hospital. These methods are controversial and distressing for all concerned and should be avoided. They are also extremely costly interventions. According to one calculation up to €280,535 was spent annually in one local hospital, almost 7% of their total acute care budget, with an average cost per episode of its management between €282.34 to €821.99 (Serrano-Blanco et al 2017). The specific direct cost of mechanical restraint is between €513 to €1,160 per episode (Garrido Viñado, et al 2015).

These considerations underline the importance of identifying symptoms of agitation early on and ideally preventing a crisis episode happening in the first place.

2. THE EXPERIENCE OF AGITATION AND ITS TRIGGERS

There is very limited research on the experience of agitation. Of the symptoms listed above, the most common include uneasiness, restlessness or nervousness.

Many episodes of agitation are mild to moderate but can be frequent. Symptoms of agitation can occur suddenly or more slowly, lasting only a few minutes or for days.

There are many possible triggers for agitation which people with lived experience have described and these can vary from person to person - for example, having too little sleep, financial worries, disagreements with others, hearing loud noises, feeling uncertain or under pressure, being in a crowded place or stuck in traffic. Agitation can be a frightening experience and a person can feel as though they are losing control.

“

I start trembling, especially my legs and hands.
I feel a sense of panic and want to escape the situation.
Sometimes I start crying. If it gets bad I sometimes lose touch with reality or faint.

(Person with lived experience)

”

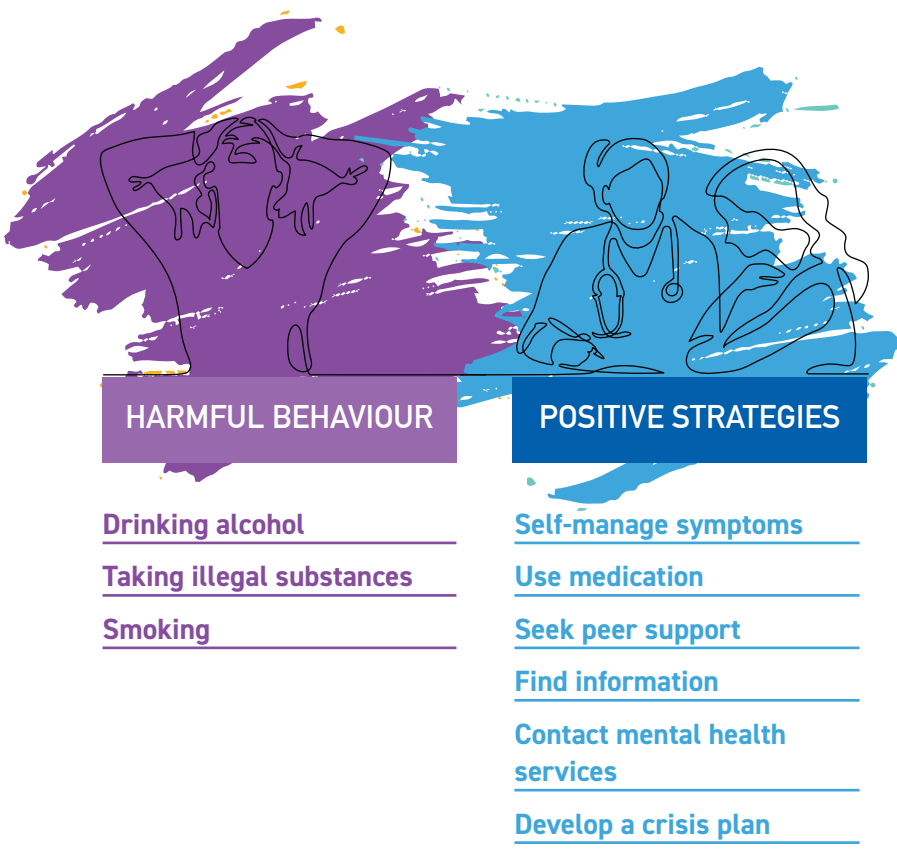
2.1 WHAT PEOPLE WHO EXPERIENCE AGITATION CAN DO

Seeking the perspectives of experts by experience and carers is essential to understanding how best to manage symptoms of agitation and in preventing a crisis episode. Many people recognise their symptoms of agitation and know what can trigger an episode. Some are able to control or manage these symptoms but for others this can be difficult even when trying out recommended techniques. Taking prescribed medication is a common strategy for people to reduce symptoms of agitation and help them to calm down (Dahlen et al, 2015). People who experience agitation can talk to family, friends and a healthcare professional to help ease symptoms. They can also recognise any signs and symptoms and suggest practical things a person who is agitated can do. It is very important for people around someone experiencing agitation to remain calm. This helps to deescalate the situation and prevent symptoms becoming worse.

Harmful behaviour includes drinking alcohol, smoking or taking illegal substances. Some people use no coping techniques and simply wait for the episode to subside. But more understanding of these strategies is needed.

Several techniques and prevention strategies have been developed over the past decade to help avoid relapse and admission to hospital for people with schizophrenia or bipolar disorder which can also be used to help manage agitation. Examples include self-management/care, peer support and a crisis plan or advanced directive.

Figure 2
POSITIVE AND HARMFUL STRATEGIES FOR MANAGING
AGITATION



2.1.1 SELF-MANAGEMENT

Education and self-management are important skills to teach both people experiencing agitation and their carers in the community. Effective self-management techniques include educating the person about his or her condition, how to manage medication, recognise early signs of relapse, develop a relapse prevention plan and gain coping skills for managing persistent symptoms (Mueser and McGurk, 2004). Self-management education has been shown to reduce relapse, hospitalisation and severe symptoms (Zou et al, 2013). There are also simple strategies which include going for a walk, meditation and distraction, although if a person is very agitated it can be difficult to use these approaches. So it is important a person finds appropriate ways that can help reduce their symptoms.

Sleep is an important way to prevent and manage agitation. Making sure you have enough sleep can be vital to preventing an episode of agitation or as a way to minimise symptoms. Going to bed early or having a nap when the symptoms of agitation start can be beneficial. Some people try to focus on other things when they become agitated.



If the [agitation] is not too long I get my thoughts shifted to my breath and focus on a long and slow way of breathing in and exhaling.

(Person with lived experience)





2.1.2 TAKE MEDICATION

Medication can often be the first line of action when managing agitation. When symptoms of agitation start people often take medication to help calm them down. Some will know exactly what they should take depending on how bad their agitation is or likely to be. It is important to understand the effects of medication and how that might add to an episode of agitation or make it worse. This understanding usually follows after experiencing a few episodes of agitation.

2.1.3 SEEK PEER SUPPORT

Peer support is the help and support people with lived experience of mental ill-health are able to give each other. This can be practical, emotional or social support and can be used to help people who experience agitation. Peer support, as part of a recovery-oriented approach is important for helping people to learn about their illness and identify useful coping strategies. Recovery-oriented approaches emphasise people's strengths and abilities and so peer support is about learning from others with the same condition who have successfully dealt with or are currently managing their psychiatric illness (Solomon, 2004). People who experience agitation and their carers provide valuable knowledge not only to their peers but also to health and social care professionals.

Many peer-led interventions for people with a severe mental ill-health condition include peer listening, mutual support groups, self-help organisations and expert by experience-led services. Research suggests these interventions can reduce hospitalisation, improve social support, attitudes towards recovery and engagement with care (Ahmed et al, 2012). However, there is limited evidence to show that peer support improves admission to hospital, overall symptoms or satisfaction outcomes in addition to treatment, but there is some evidence to suggest improvements in the recovery process (Lloyd-Evans et al, 2014). There are peer-delivered self-management programmes with a peer support worker that have been found to be valuable in helping people after a crisis.



Support includes setting personal recovery goals, reestablishing support networks, identifying early signs and symptoms, planning strategies to avoid relapse and maintaining well-being (Johnson et al, 2018).

Online peer support networks (via social media, for example) provide another opportunity by which peers can support and empower each other, but any potential risks, such as exposure to hostile or negative comments must be regulated (Naslund et al, 2016).



2.1.4 CREATE A CRISIS OR ACTION PLAN

It is important to plan and prepare in advance what to do in the event of a crisis. One way to do this is to create a crisis plan or advanced directive. These are statements written in advance to detail what treatment or intervention a person would like in the event of a crisis episode. These legal documents might be in the form of a card, kept electronically or in a person's healthcare records. It can contain information about their mental health diagnosis, their symptoms, a contact number of someone trusted, a list of signs or symptoms (including agitation), current medication and other important details (e.g. for emergency services).

A crisis plan can be jointly written with an advocate, carer, friend and the person's clinician and lends itself well to managing symptoms of agitation, especially during an admission to hospital. The development of a crisis plan allows people to feel more autonomous, respected as a person and in control of their condition. Many clinicians regard these plans as positive, although they are still to be widely used (Maître et al, 2013).

Having an agreement or crisis plan with someone you trust is important.

That person can let you know when you are becoming agitated and call for professional help if necessary. Talking to the person, asking whether they would like to take medication and what they need is helpful. Having a good relationship with a carer and accessible and timely care (especially out of hours) are also important in a crisis. People with lived experience felt that having feedback on symptoms (for example, 'you seem a bit anxious') was very helpful so too was taking rescue medication when manic, psychotic or agitated.

When completing an advanced directive it is important for people in the close environment to be given information about the procedures and treatments used during a crisis. This will help the person make more informed decisions and about their preferences. Some services have created a facilitated session for this purpose which includes an interview and guided discussion of choices (Swanson et al, 2006). This has been shown to be effective for producing crisis plans that are feasible for treatment in the community or during hospitalisation; and can also lead to better relationships with clinicians (Swanson et al, 2006). If the agitated person is able to choose their preferred medications as stated in their advanced directive, they are more likely to adhere to them even in non-crisis situations (Wilder et al, 2010).

The Mental Health Crisis Care Concordat (2014) is a useful guidance document which outlines what people experiencing a crisis should expect from professionals who come to help them. This provides different types of triage and sanctuary for a few hours. The person in crisis should not be taken to a police station as a place of safety. The environment of care is important which should be safe and appropriate.



3. CARERS' EXPERIENCE

Many people diagnosed with a severe mental ill-health condition such as schizophrenia or bipolar disorder often live or remain in close contact with an informal carer.

This person is usually a close family relative, such as a parent, partner, sibling or child, but often this is defined by the person. There are also formal or professional carers who work within mental health services.

Although caring for someone with a lifelong severe mental ill-health condition can include positive experiences, such as finding inner strength, the experience can be very distressing and challenging for the carer (as well as the person), especially during a crisis and admission to hospital (EUFAM1a). Carers play a key role in helping to organise care and treatment from the person's first episode of illness through to any subsequent relapses and in addressing any needs not met by services (EUFAM1b; Kuipers et al, 2010). It can be a full-time role with carers providing up to 38 hours or more of care a week. Carers help support their relative in a variety of ways including managing their finances, help with transportation and meals, managing medication and contributing to treatment decisions (EUFAM1b). This support is invaluable and has been shown to lead to fewer admissions and relapses, better engagement with services, adherence with medication and lower mortality rates. Support for carers therefore is very important (Vermeulen et al, 2015).

The impact of caring for someone specifically experiencing an episode of agitation can be similarly challenging. Many carers will worry about the person they are caring for, some will urge them to do what is needed and others will feel mostly tense or anxious (Blanthorn-Hazell et al, 2018).

3.1 WHAT CARERS CAN DO

In most cases carers are able to recognise an episode of agitation. There are a number of techniques carers of people with schizophrenia or bipolar have been found to use and most carers will intervene at a point when the episode of agitation is of mild or moderate intensity rather than wait until it becomes severe (Blanthorn-Hazell et al, 2018). For the most part, the techniques carers use include verbal de-escalation, such as talking to and soothing the person and helping with supervising rescue medication. Few carers will resort to physically restraining their relative, which is not recommended and should be avoided.

Coping strategies used by carers of relatives with dementia who become agitated have found they can prevent agitation by maintaining a familiar routine, addressing the underlying causes, using distraction, controlling their own emotional reactions, making time for themselves and accessing services for emotional and practical help (Hoe et al, 2017). People who experience agitation have described what their carers do to help when they feel agitated. Offering reassurance and listening emphatically are among the best approaches carers can use.



When they [people, carers, professionals] act like they understand, and reassure, the agitation tends to go down more easily.

(Person with lived experience)



Talk gently to me, reassure me that there is no threat. Stroke my arm or shoulder.xhaling.

(Person with lived experience)



Avoiding negative comments and trying to explain things in a gentle and calm manner are what carers describe as helpful.

“

I try to get him to rationalize the situation, take the sense of urgency out of it...and to calm him down.

(Carer)

”

“

Any experience where psychosis occurs is a difficult situation. It requires full attention from the [carer] and best with a calm behaviour and a general voice.

(Carer)

”

Creating or taking someone to a safe and neutral space is another effective way to ensure they do not feel trapped, closed in or overstimulated. This might be a quiet, relaxed or darkened room. Carers can keep also keep a record of techniques that have helped relieve symptoms or stress and encourage the person to practice them (e.g. meditation, going for a walk). Seeking support and advice from a professional, especially from someone who already knows you and the person you care for can be important for preventing agitation escalating into a crisis (see Section 4 below).

Figure 3
STRATEGIES FOR CARERS TO HELP MANAGE AGITATION



one

Recognise
symptoms early

two

Create a quiet
and safe space



three

Listen
emphatically
and offer
reassurance



four

Avoid negative
comments



five

Seek advice and
support from a
professional





3.1.1 HOW CARERS CAN LOOK AFTER THEMSELVES

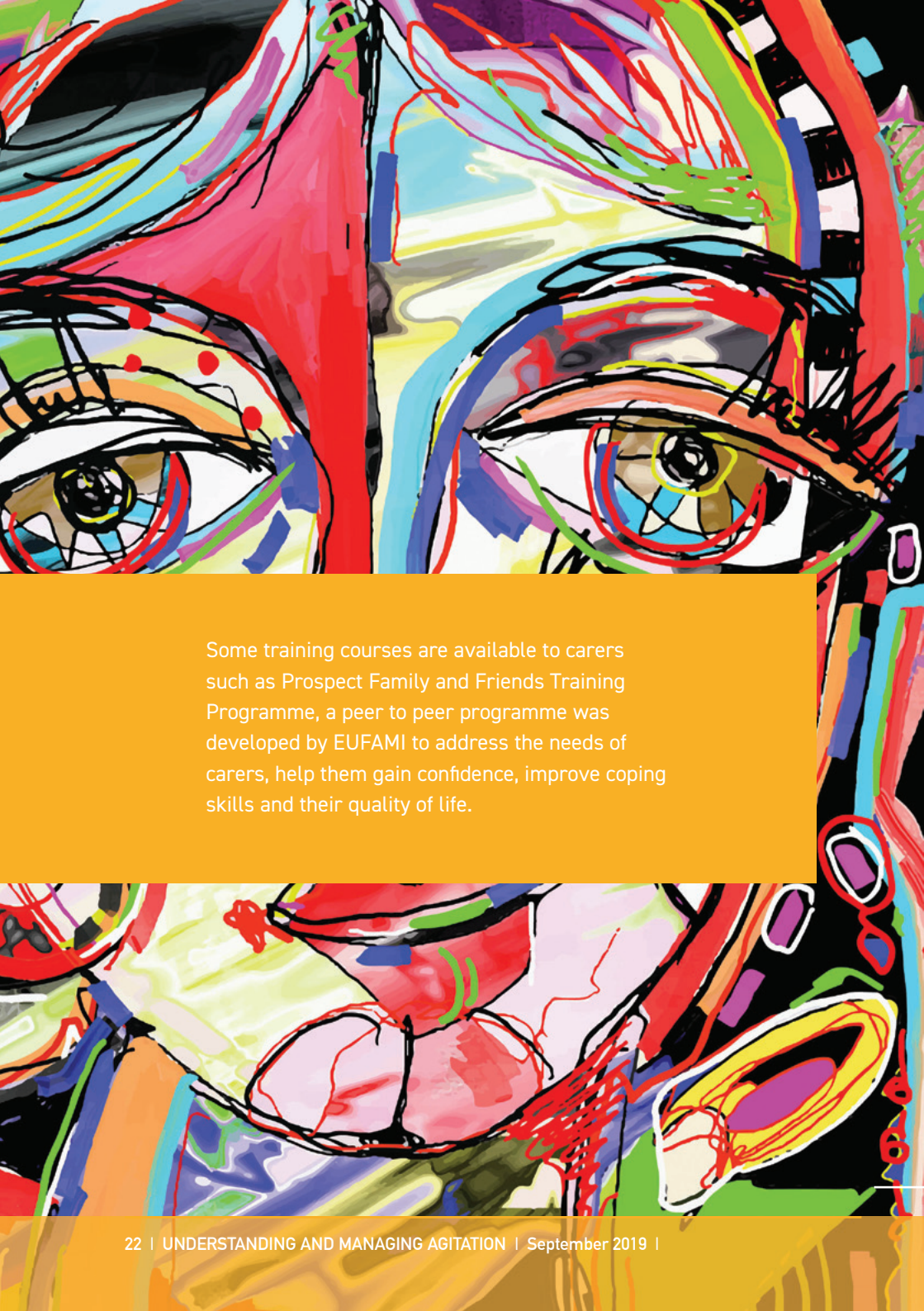
It is not unusual for carers of people with a severe mental ill-health condition to feel their own needs are overlooked and neglected (Onwumere et al, 2016). Help from mental health professionals and services for carers is not always readily available. Carers often report difficulties with timely access to services for their relative and not being listened to by professionals (EUFAMIC).

It is important carers receive the support they require not only for their physical and mental health, but also in finding ways to cope and manage their situation well. MIND in the UK¹ provide ten helpful tips on how to cope.

¹ <https://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family/looking-after-yourself/#talk>

Figure 4
TOP TIPS FOR CARERS TO LOOK AFTER THEMSELVES





Some training courses are available to carers such as Prospect Family and Friends Training Programme, a peer to peer programme was developed by EUFAMI to address the needs of carers, help them gain confidence, improve coping skills and their quality of life.

4. PREVENTION AND TREATMENTS

4.1 PREVENTION AND EARLY INTERVENTION

Diagnosing and treating the main health condition, such as schizophrenia or bipolar disorder and recognising and treating agitation as part of that are key to prevention. Agitation is often a sign of these main conditions, so if treated properly will usually reduce in intensity or disappear. Acting fast and intervening early, when the signs and symptoms of agitation begin to emerge, avoids many of the most distressing and uncomfortable feelings associated with it. More importantly it can help prevent agitation turning into a crisis.

4.2 MEDICATION AND TREATMENT FOR ACUTE EPISODES

Pharmacological treatments continue to be the primary intervention for people with schizophrenia and bipolar disorder. When a person experiences a severe episode of agitation/crisis they may need an admission to hospital. However, alternatives to hospital are available which help reduce some of the distress and stigma associated with an admission. These services are called Home Treatment, Crisis Resolution or Intensive Home Treatment Teams where the crisis is assessed and managed at home by a team of professionals. These teams can also facilitate early discharge from hospital if a person is admitted. Further research is being carried out to understand the effectiveness of home treatment for a crisis episode (Cornelis et al, 2018; Carpenter et al, 2013).

Guidelines for clinically managing a crisis episode have been produced and are based on de-escalation, pharmacological interventions and rapid tranquilisation (Patel et al, 2018). A range of pharmacological treatments are used to reduce the symptoms of agitation. These include anti-psychotics (e.g. olanzapine, risperidol) and benzodiazepines (e.g. lorazepam) given either orally or by injection (Zeller and Rhoades, 2010).

Maintenance medication is important too and some people who experience agitation and their carers know what medication to use in response to the early signs of agitation.

“

...the right maintenance medication helps me to avoid severe agitation periods, and thus being controllable.

(Person with lived experience)

”

Recent advancements specifically for treating an episode of agitation include the development of a fast acting inhaler (Loxapine) or rescue medication. This has been tested with people experiencing agitation prior to being taken to emergency psychiatric services (Cester-Martinez et al, 2017), and its safety and efficacy checked (Pacciardi et al, 2019). The advantages of this inhaler is that it can be self-administered, is non-coercive, acts rapidly to manage symptoms of agitation and faster than when given by injection (San et al, 2018). This in turn could help to avoid admission to hospital, the possibility of containment or the use of physical or mechanical restraints. Its use at home without the need for supervision from a healthcare professional is being researched (Gil et al, 2018).

4.3 TALKING THERAPIES

The use of psychological therapies, mainly cognitive behavioural therapy can also be effective for treating symptoms (Pfammater et al, 2006), especially for those who prefer not to rely solely on adding medication when agitated. Although there is limited research on the effectiveness of talking therapy to preventing and managing symptoms, particularly when identifying early signs and in knowing what to do. This approach offers an important alternative for people who experience agitation which carers consider helpful.

“

We did finally get the mental health service to give him some talking therapy, which has helped a little.

(Carer)

”

“

Talking therapy should be offered as an ongoing support to people with chronic schizophrenia.

(Carer)

”

5. SEEKING HELP FROM MENTAL HEALTH SERVICES

5.1 CONTACT AND RELATIONSHIP WITH MENTAL HEALTH SERVICES

People experienced at managing their agitation and their carers may have developed an understanding with mental health services and can contact their mental health professional (a psychiatric nurse or psychiatrist) when concerned.

If a mental health professional knows a person well they will know what strategies to use to help calm them down. Access to a telephone helpline can also be useful and reassuring, especially in the early stages of agitation. The contact person could be another person with the same experience, peer supporter or professional who could be called for advice. It is important that the hospital or professional has access to good case notes on the person and knows in advance what strategies help them during their episode of agitation.

Some people have learnt to manage their agitation without the need to contact mental health services.



After many years of experience I have learnt to cope with it by myself.

(Person with lived experience)



Non-psychiatric services may struggle to identify and manage agitation in someone with a serious mental health problem.

“

Sometimes I will go to the emergency room of the general hospital, but they don't always take my symptoms seriously. Mostly if I go there it is because someone or an ambulance brought me there.

(Person with lived experience)

”

If symptoms of agitation become severe enough admission to a psychiatric hospital may be necessary, although this is not always easy.


“

It would be a relief if [my son] would be admitted for a short period in a kind of crisis center where they would manage the acute period. Previous admissions to a psychiatric hospital have left him with such a fear for a new admission, even mentioning the possibility makes him unmanageable. Compulsory admission is something we want to avoid at any time.

(Person with lived experience)

”





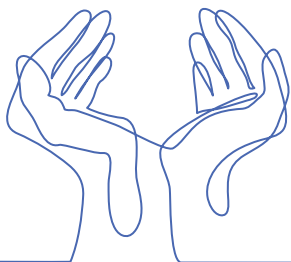
Careful preparation and management of any hospital admission process for an acute episode of agitation is therefore essential. Ideally this would include a crisis plan or advanced directive as described in Section 2.1.4). This should include the way in which pharmacological treatment is administered and how agitation is managed during an admission and handled sensitively in accordance with the person's wishes. Building trust and good relationships with all those involved is critical to minimising the distress linked to a hospital admission.

5.2 HOW PROFESSIONALS DEAL WITH AGITATION

There are now published protocols and guidelines for professionals who manage people experiencing agitation and again emphasise the importance of avoiding the use of restraint. These protocols have been developed for healthcare professionals and for staff working with emergency services, such as the police. It is important that these professionals follow these protocols so that people experiencing an episode of agitation are diverted away from police custody and referred quickly to the right services².

Professionals, for the most part see uncontrolled agitation states and not always the levels experienced by people and carers at home (Roberts et al, 2018; Rubio-Valera et al, 2016). As a result protocols and guidelines to manage agitation mostly cover acute episodes of severe agitation in emergency departments or hospital wards. More emphasis has been placed on using non-coercive practices such as verbal de-escalation, rather than routine restraints and involuntary medication (Richmond et al, 2012). In terms of best practice there are four main objectives for emergency departments and psychiatrists when dealing with agitation:

² <https://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/looking-after-yourself/#talk>

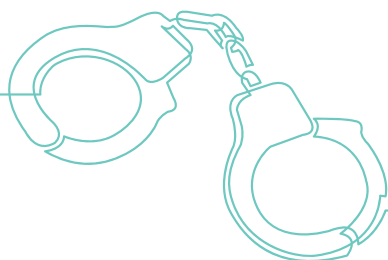


one

Ensure the person's
and other people's safety

two

Help the person manage
their emotions and distress
or enable them to resume
control of their behaviour



three

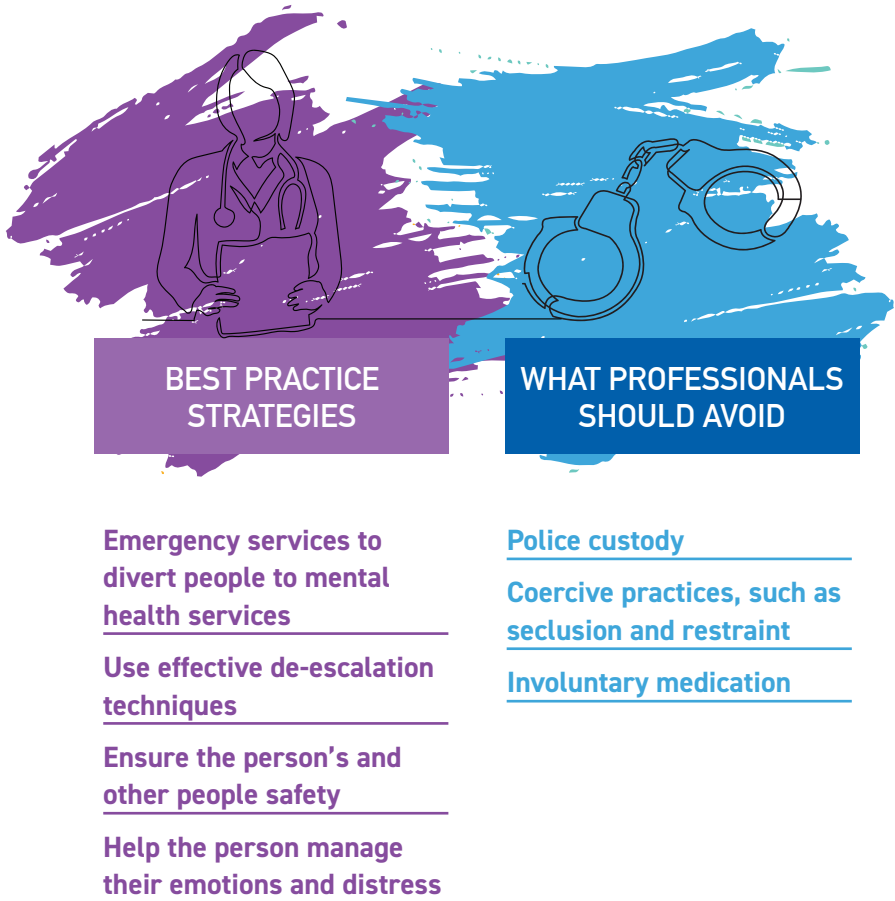
Avoid using restraint
as far as possible

four

Avoid coercive interventions
that make the person's
agitation worse



Figure 5
BEST PRACTICE STRATEGIES FOR PROFESSIONALS
AND WHAT THEY SHOULD AVOID



There is little research on the best techniques for verbal de-escalation in emergency settings but clinicians who regularly work with people experiencing an episode of agitation often perfect ways of dealing with this. But training is important to teach professionals de-escalation skills. De-escalation starts by listening to the person, acknowledging their position and then the clinician can explain what s/he would like the person to do. Physically trying to calm an agitated person is not advisable and clinicians will also need to know how to manage their own negative reactions and emotions.

Security and police officers who encounter people experiencing agitation must recognise that their behaviour may well be part of a mental illness. For these professionals de-escalation is again the preferred method of intervention. It is not enough for the police to be solely educated about mental illness, but also to be trained by experts by experience and carers to fully understand what this means. Building good relations is important too.

There are a number of good practice examples of police-based teams who have been trained by mental health professionals to respond to people experiencing a crisis episode or acute agitation. The Crisis Intervention Team model of police response is one example which aims to address the needs of the people in an emergency by diverting them away from the criminal justice system and connect them to mental health services (Watson and Fulambarker, 2012). One police force in Barcelona has now developed a new protocol for managing people experiencing severe agitation³. The protocol was jointly developed by a number of different agencies, including the Emergency Medical Service. The intervention strategy attempts to improve support from the time agitation begins until they leave hospital, if they were admitted.

³ https://www.barcelona.cat/infobarcelona/en/new-police-protocol-to-deal-with-people-in-a-serious-state-of-agitation_788471.html



6. SUMMARY

Agitation is a common experience and usually part of a severe mental ill-health condition rather than an illness in its own right. When uncontrolled or severe, agitation is distressing for the person experiencing it and the people close to them. Treatment for agitation is multi-dimensional and does not only include medication, but various strategies to help a person stay calm. Using coercive or restraining measures are recognised as inappropriate and to be avoided. De-escalation techniques and giving medication are the preferred options for anyone having to help someone experiencing agitation.

Carers play a valuable role in identifying and managing symptoms of agitation in their friend or relative. They are well placed in helping to de-escalate these situations and supervise rescue medication. These initial interventions can prevent an admission to hospital.

Recognising the early signs of agitation means people who experience this can use positive techniques that work for them. Using self-management approaches, peer support, having a crisis plan and taking medication are effective.

Support from professionals for people experiencing agitation and those that care for them is essential. Working collaboratively to ensure this experience is kept to a minimum and prevented from escalating or happening in the first place is similarly important.

A call for action for all stakeholders is needed in relation to managing agitation. This would empower people who experience agitation and their caregivers to identify and act more promptly in the event of an episode of agitation. It should also aim to promote the implementation of best practice protocols and training amongst professionals so that they use non-coercive or seclusion approaches at every opportunity.

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