

The Be-Well Checklist



Helping parents, carers and professionals to reduce challenging behaviour and improve the wellbeing of people with severe learning disability and complex needs



Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., Pearson, E., Richards, C., Waite, J., Welham, A., Wilde, L., and Woodcock, K.



Background to the Be-Well Checklist

When someone has a severe learning disability and complex needs, it can be difficult to know how they are feeling or why they are showing a particular behaviour.

Research and clinical experience shows us that when it comes to challenging behaviour and wellbeing, the most important things to consider are: pain and discomfort, sensory sensitivity, anxiety, sleep difficulties, emotional control, impulsivity, insistence on sameness, and differences in social behaviour¹. These things can each cause particular behaviours and affect someone's quality of life and they are often linked to each other. Each of these areas is described and explained in the checklist on pages 14 and 15.

It is also very important to consider whether challenging behaviours lead to a person accessing something they need or want, and whether the person has difficulties communicating to others what they need or how they feel. Not having the means to access things, activities and people can cause challenging behaviours and reduces quality of life. Challenging behaviours that lead to a person accessing something they need or want, or let others know what is needed, are often called learned behaviours.

Making sure that these things are thought about, checked and assessed is the first step to improving wellbeing and behaviour but it can be hard to know where to start. So it is helpful for carers, parents and professionals to have a list of things to work through together and keep track of someone's behaviour and wellbeing. The Be-Well Checklist is a tool to help everyone involved to do this.

¹ There is a journal article that covers this information in more detail. Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., Richards, C., Waite, J., Welham, A., Wilde, L., and Woodcock, K. (2020). [The behaviour and wellbeing of children and adults with severe intellectual disability and complex needs: the Be-Well checklist for carers and professionals](#). *Paediatrics and Child Health*, 30, 416–424.

What is the Be-Well Checklist?

The Be-Well Checklist is a list of the things that are important to assess when thinking about the behaviour and wellbeing of children and adults with severe learning disability and complex needs. Using the list makes sure that these things are not missed or forgotten. The checklist is in two parts: the Be-Well Checklist itself that describes the items and what to look for and the Be-Well Record that keeps track of what might be important and how things are going.

When is the Be-Well Checklist useful?

The Be-Well Checklist can be used by parents, carers and professionals when they are trying to work out why someone is showing a behaviour or might be distressed, angry, upset or appear to have very low mood. It can also be used at regular review meetings or any other time to make sure someone's quality of life is as good as it can be. It can help make sure the right things are all discussed and thought about and help everyone to agree on the most important things to do next. Carers, parents and professionals can then decide together which assessments and treatments might be helpful.

Who is the Be-Well Checklist for?

The Be-Well Checklist is useful for children and adults who have a severe learning disability and complex needs. This means people who need a lot of support in their daily life and who often find it hard to tell other people what they need or want, or how they feel. They might also have physical disabilities or problems seeing and hearing as well as some autistic characteristics or a genetic syndrome.

Before using the Be-Well Checklist

It is important to know if someone is autistic and, if possible, the cause of their disability. This helps everyone to be aware that some items on the checklist might be more common than others or that problems might be unusual in how they appear.

None of the items on the checklist are caused by a learning disability, autism or a genetic syndrome. They are just more common in people with these characteristics. Before using the checklist it is also important to be sure that seizures (epilepsy) and medications have been thought about and reviewed.

The checklist covers things that are characteristics of the person but it does not cover things in the environment that might also be important, such as relationships with others, whether activities are available and how much choice someone has. These can also affect behaviour and wellbeing.

Using the Be-Well checklist helps to think about how someone experiences the world and the way in which the environment could change to best fit with the person. You can find further information on checklist items on the [Cerebra website](#) or on www.findresources.co.uk.



Using the Be-Well Checklist and the Be-Well Record

It always helps to keep a record so everyone can see if behaviour and wellbeing are improving over time. It also helps to go through the checklist items regularly and make sure everything has been kept in mind, see if anything has changed or if something needs to be assessed or given more attention.

- To get started, have both the Be-Well Checklist and the Be-Well Record open in front of you.
- Next, read through the items on the Be-Well Checklist and the descriptions of the signs so that you are familiar with items on the list.
- Next, read through the instructions for using the Be-Well Record and how to use the rating scales.
- Now, describe the challenging behaviours you want to reduce (if there are any) and rate these and think then about overall wellbeing and rate this.
- Next, rate each of the checklist items.

Rating challenging behaviour

If your goal is to reduce a challenging behaviour, then the behaviour rating gives you a baseline of

1. how frequently the behaviour is occurring and
2. how difficult it is to manage.

Ideally, we want to see both these ratings come down over time. Most clinicians would consider a rating of 4 or 5 on either scale as showing the behaviour is severe.

How to rate a challenging behaviour that you want to focus on

- Name the behaviour(s) as clearly as you can so everyone knows what is meant (e.g. hitting others, banging his head on objects or surfaces, screaming, throwing herself to the floor, knocking objects over etc.). Sometimes it can be hard to think about which behaviour to focus on if many occur together. If so, ask yourself what harm does a behaviour do, what effect does it have on the person and others, and how concerned you are about the behaviour.
- Think about how frequently the behaviour has occurred in the last two weeks and give it a rating in the "Frequency" box based on when you think you would definitely see the behaviour:

5

In the next 15 minutes

4

In the next hour

3

By this time tomorrow

2

By this time next week

1

By this time next month

- Think about what happens when the behaviour occurs and rate in the “Response” box how often it has been necessary for someone to respond by preventing or stopping the behaviour:

5

At least once an hour

4

At least once a day

3

At least once a week

2

At least once a month

1

Never

- Use the Be-Well Record to keep a note of the ratings and the date on which they were made.

Rating wellbeing

This rating gives you a baseline.

Over time, we would want to see the rating go down to 2 and preferably 1.

Ratings of 4 or 5 means that action should be taken.

How to rate wellbeing

- Think about the last two weeks and how you would describe the person's mood generally on a typical day and then rate it:

5

Very distressed for long periods

4

Frequent episodes of distress that lasted a while or were quite noticeable

3

Some episodes of distress that lasted a while or were quite noticeable

2

Very occasional minor distress or very brief episodes of distress

1

No signs of distress at all

- Use the Be-Well Record to keep a note of the rating and the date it was made.

Rating checklist items

For each item, remind yourself of what the ratings mean and then rate each item. For communication, there are nine ratings to make.

How to rate checklist items

- Think about the last two weeks and think about the signs for each item on the checklist. Then rate each item using this scale:

4

Definitely signs of this and a significant concern

3

Definitely signs of this and causes concern

2

Some signs of this but not really a concern

1

No signs of this at all

N/S

Not sure, need to check this

How to rate communication items

- Look at the brief description of each communication item.
- Note the date at the top of the column.
- Rate each communication item using this scale:

4

Not at all or very hit and miss

3

Some of the time

2

Most of the time

1

All of the time or very nearly

N/S

Not sure, need to check this

Looking over your ratings and deciding what to do

Any checklist item that is rated 3 or 4 or not sure (N/S) could be an underlying cause of a behaviour or poor wellbeing, might have a negative influence on behaviour or wellbeing, or could be related to other checklist items. The items you have rated as 3, 4 or N/S need attention. This might mean finding out more about that item before you take the next step. These items should be high on the list of priorities for action.

The most important thing to do next is to talk about the item(s) with all those involved with the person (carers, doctors, teachers, speech and language therapists, behaviour support teams etc.). Take your checklist with you to use as a reminder of things to talk through and make copies for people.

The goal is to decide with others which items should be thought about first and what should now be done. For checklist items rated 3, 4 or N/S, at the very least there either needs to be further assessment or there needs to be a plan in place to understand how an item might be related to other items with regular review of how well that plan is working. This action plan should say who is going to do what and by when.

The most important thing to remember at this point is "It doesn't have to be like this." Behaviour and wellbeing can be improved.

Doing the ratings again

Ratings can be repeated anything from fortnightly to monthly to see if any plan is working. Change does take time but keeping a record helps everyone see if things are moving in the right direction and helps to share information and agree if more or less needs to be done or something needs to be changed.

An example:

Peter is 7 years old and has a severe intellectual disability and shows some autistic characteristics. He is able to walk and can use a few Makaton signs but he needs help with all self-help activities (e.g. dressing, feeding). His hearing and vision are both good and he is not on any medication. His sleep is mostly good but there are some very bad nights when he can't seem to settle and then wakes a lot during the night. Peter hits out at others on occasion. He also bangs his head on tables and walls and slaps his face and can appear quite distressed at these times. Both of these behaviours leave red marks and Peter's parents are worried about the behaviours as it means they cannot take Peter out as much as they would like to and the behaviours can just start without them seeing a trigger.

● Rating the behaviours

Peter's parents estimate that the head banging is likely to happen at least once in the next hour and that by this time tomorrow they will have had to prevent Peter from banging his head at least once. They decide to focus on this behaviour and so on the Be-Well Record they name the behaviour "banging head on objects or surfaces" and rate the *frequency* as 4 and the *response* as 4.

Next, Peter's parents think about Peter's mood over the last two weeks and they remember that there were days that Peter was quite distressed and they were not able to comfort him. So, on the *wellbeing scale* they rate Peter at a 4 because the distress wasn't frequent but it was noticeable when it happened.

The Be-Well Record for behaviour and wellbeing					
Date	6th Oct				
Behaviour 1 to change is:	<i>Banging head on objects or surfaces</i>				
Frequency (rate from 1 to 5)	4				
Response (rate from 1 to 5)	4				
Behaviour 2 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 3 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Wellbeing (rate from 1 to 5)	4				

- Next Peter's parents read through the checklist items

For *pain and discomfort*, they can see some of the signs seem to apply, such as the behaviour comes out of the blue sometimes and there is distress at the same time. They rate it 3.

For *sensory sensitivity*, they are not sure if this applies as he has never had an assessment and it hasn't been discussed at school meetings. They rate it N/S.

For *anxiety*, they haven't seen many of the signs but occasionally they might see them when they are at the weekly supermarket visit. They rate it 2.

For *low mood*, although there are periods of distress these don't last that long, so they rate it 2.

For a 7 year old, both *sleep difficulties* and *emotional outbursts* are happening more than would be expected. They rate each item 3.

Peter is quite good at waiting for things but does have a strong preference for routine but they can usually work around this. They rate *impulsive* 1 and *insistence on sameness* 2.

For *social differences* Peter doesn't really avoid others but also he doesn't seek others out. They rate it 2.

For *learned behaviour* they are not sure if the signs apply as they are so concerned with managing the behaviour when it happens. They rate it N/S.

Checklist items (rate from 1 to 4 or N/S)					
Pain and discomfort	3				
Sensory problems/sensitivity	n/s				
Anxiety	2				
Low Mood	2				
Sleep	3				
Emotional outburst	3				
Impulsive	1				
Insists on sameness	2				
Social differences	2				
Learned behaviour	n/s				

- Now Peter's parents rate the **communication items**

For the communication items, they know he can always ask for food, drink, most objects he would want, social contact if he wanted it and things to start by using his Makaton signs and leading people by the hand. They rate each of these 2.

For wanting things to stop, help or to go somewhere they are not sure if he can do these with everyone so they rate them N\S.

Looking back over the Be-Well Record, Peter's parents now have a baseline rating for "banging head on objects and surfaces" (frequency = 4, response = 4) and wellbeing (4). They can now make the same ratings every two weeks to see if they are decreasing. If so, this shows the behaviour is reducing and wellbeing is improving.

Deciding what to do

Given the high scores for the headbanging, Peter's parents can ask those services and professionals involved with Peter for assessment and intervention and can use the checklist to discuss possible causes. This always takes some time, so in the meantime they can look at other checklist items and try to move ahead by raising some of the issues with their GP and finding more information.

For the checklist items, Peter's parents can see that they are not sure (N\S) about sensory sensitivity and if the behaviour might be learned. Also, they are not sure about how reliably Peter can communicate that he wants things to stop, needs help or wants to go somewhere. They decide to ask at Peter's school if these three areas have been assessed. If they have, then they might be able to change their ratings based on the information they get and if they have not then the assessments can be requested. They also download the [Sensory Sensitivity](#) guide from the Cerebra website so they know what to look for and ask about.

For other items on the checklist, three are rated 3. There are possible signs of pain and discomfort, there are some sleep difficulties and there are emotional outbursts. These three areas are a priority. Peter's parents make an appointment with Peter's GP to discuss these three areas specifically and in particular to request a physical assessment for possible causes of pain and advice on sleep difficulties. They also make a dental appointment for a check-up and download the [Pain](#) and [Sleep](#) guides from the Cerebra website.

When meetings with Peter's school or any support teams involved take place, Peter's parents take the checklist along with them and ask that the agenda includes: 1) all items that are rated N\S, 2) behaviours that are rated 4 or 5, and 3) checklist items that are rated 3 or 4. For each of these items they ask for an action plan that states who will do what and by when and that at the next meeting each of the action plan items is discussed and reviewed.

Whilst any assessments and interventions are ongoing, Peter's parents continue to rate his headbanging and wellbeing every two weeks and the checklist items every month.

The Be-Well Checklist

Each item has some signs to look for and a note of other checklist items that are linked with the item.

	Signs to look out for	Notes
Pain and discomfort	Facial expression (two lines in forehead), crying\groaning\screaming, cannot be comforted, frequent leg movements, unable to be still, defends a body area. Behaviour or negative emotion occurs out of the blue.	Affects sleep. Can cause the behaviour to start in the first place and then later becomes learned. Can make learned behaviours more likely to occur.
Sensory sensitivity	Moves away from, refuses to be near or avoids noises, textures, lights, temperatures	Can affect sleep. Can cause phobias to develop. Can be a trigger for learned behaviours and anxiety.
Anxiety or low mood	<p>Anxiety: Moves away from, resists, refuses to be in or avoids situations or events. When in situations or events seeks reassurance or clings to someone. Appears fearful or tense (muscles are tense). Might stay in a situation or event but is fearful, tense and distressed.</p> <p>Low mood: doesn't enjoy activities or being with people, low levels of interest in things around them, rarely smiles or laughs (if at all).</p>	<p>Anxiety: Can affect sleep, and pain and discomfort. Can be a response to sensory sensitivity, or unpredictable events or situations. Can be a trigger for learned behaviours. Can cause low mood.</p> <p>Low mood: can be caused by pain and discomfort, anxiety, environments that are unstimulating or lack choice and opportunity.</p>
Sleep difficulties	(As appropriate for age and family's preference). Wakes during the night or very early, cannot settle to sleep, needs to sleep with parent or carer, snores a lot, sleepy in the day.	Can be caused by anxiety, pain and discomfort, or breathing difficulties. Poor sleep can make impulsivity and learned behaviours more likely.
Emotional outbursts	(As appropriate for age). Outbursts of emotion that are out of proportion to the cause. Outbursts include: crying, screaming, face being red, distress. Unable to calm self or be calmed.	Can be triggered by events in the same way as learned behaviours and by anxiety, changes in routine and things that are wanted being delayed.

<p>Impulsive or insists on sameness</p>	<p>Impulsive: cannot wait, needs instant response, cannot put the brakes on.</p> <p>Insists on sameness: must have routine, resists or dislikes change, checks things a lot, tidies and arranges a lot.</p>	<p>Can make anxiety, learned behaviours and emotional outbursts more likely.</p> <p>Insistence on sameness might be a response to anxiety. Can lead to avoiding events or places.</p>
<p>Social differences</p>	<p>Preference: seeks out people or a specific person, strong reaction if not able to be with others.</p> <p>Avoidance: Moves away from or refuses to be with others. Avoids social events or activities.</p>	<p>Can be related to anxiety (social anxiety). Can make learned behaviours more likely.</p> <p>Can be related to sleep difficulties.</p>
<p>Learned behaviour</p>	<p>Behaviour is triggered by something such as being asked to do something, go somewhere, stop doing something, someone moving away from the person, being refused or unable to get something, going into a specific place. Behaviour tends to stop when the trigger is removed or stops.</p>	<p>Probably the most common cause of behaviours but is affected by nearly all other checklist items.</p>
<p>Communication</p>	<p>As an absolute minimum, the person should be able to reliably and effectively communicate these nine things: that they want or need something to start, stop or pause, that they want or need to leave a situation or event, and that they want or need social contact, to go somewhere, food or drink, activities or help.</p>	<p>Being able to communicate these things decreases the negative impact of most other checklist items on challenging behaviour and wellbeing.</p>

The Be-Well Record for behaviour and wellbeing

Date					
Behaviour 1 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 2 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 3 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Wellbeing (rate from 1 to 5)					
Checklist items (rate from 1 to 4 or N/S)					
Pain and discomfort					
Sensory problems/sensitivity					
Anxiety					
Low Mood					
Sleep					
Emotional outburst					
Impulsive					
Insists on sameness					
Social differences					
Learned behaviour					
Communication: Wanting or needing:					
Something to start					
Something to stop					
Social contact					
Food					
Drink					
An activity or object					
Help					
To go somewhere					

The Be-Well Record for behaviour and wellbeing

Date					
Behaviour 1 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 2 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 3 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Wellbeing (rate from 1 to 5)					
Checklist items (rate from 1 to 4 or N/S)					
Pain and discomfort					
Sensory problems/sensitivity					
Anxiety					
Low Mood					
Sleep					
Emotional outburst					
Impulsive					
Insists on sameness					
Social differences					
Learned behaviour					
Communication: Wanting or needing:					
Something to start					
Something to stop					
Social contact					
Food					
Drink					
An activity or object					
Help					
To go somewhere					

The Be-Well Record for behaviour and wellbeing

Date					
Behaviour 1 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 2 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 3 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Wellbeing (rate from 1 to 5)					
Checklist items (rate from 1 to 4 or N/S)					
Pain and discomfort					
Sensory problems/sensitivity					
Anxiety					
Low Mood					
Sleep					
Emotional outburst					
Impulsive					
Insists on sameness					
Social differences					
Learned behaviour					
Communication: Wanting or needing:					
Something to start					
Something to stop					
Social contact					
Food					
Drink					
An activity or object					
Help					
To go somewhere					

The Be-Well Record for behaviour and wellbeing

Date					
Behaviour 1 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 2 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Behaviour 3 to change is:					
Frequency (rate from 1 to 5)					
Response (rate from 1 to 5)					
Wellbeing (rate from 1 to 5)					
Checklist items (rate from 1 to 4 or N/S)					
Pain and discomfort					
Sensory problems/sensitivity					
Anxiety					
Low Mood					
Sleep					
Emotional outburst					
Impulsive					
Insists on sameness					
Social differences					
Learned behaviour					
Communication: Wanting or needing:					
Something to start					
Something to stop					
Social contact					
Food					
Drink					
An activity or object					
Help					
To go somewhere					



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