



**Stay Inside:
Be Inspired**

A guide to help families, carers and support staff understand and use Active Support, so that things become more manageable and enjoyable during these challenging times.

University of
Kent

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Centre

**United
Response**
support that changes with you

Stay Inside: Be Inspired

The world has changed dramatically as a result of the Covid-19 crisis – many of the places we visit, where we work and socialise, are closed or have restricted access and we are required to self-isolate or socially distance ourselves from our friends and family. The lives of everyone is being limited and we're all having to make changes to the ways we live together, and in communities, to combat the virus.

There is plenty of general advice out there about how to adapt and cope at this difficult time. It consistently recommends these strategies:



Changing our lives in this way is difficult for all of us, but can be particularly difficult for children and adults with learning disabilities and/or autism who:

- have difficulties understanding what's happening and why
- have lost the predictability and consistency of their daily routines and structure
- suddenly have limited or no access to community activities
- are no longer able to have physical contact with friends & family
- are experiencing fear of getting the virus, or of the changes that might happen because of it
- have had to move home or are being shielded
- are being supported by agency or relief staff who don't know them well and need specific and person centred support.

There's a wide range of resources available to help families and support staff, including accessible information on understanding the virus and how to keep people healthy and safe. We're finding new ways for people with learning disabilities and/or autism to maintain contact with friends and family, and there are lots of forums and websites sharing ideas for new, creative activities at home. So we're not going to reinvent the wheel!

Instead these resources focus on the use of Active Support to enable families and support staff to develop the skills needed to support people with learning disabilities and/or autism in **Staying active and trying new things** and **Creating structure and routine**.

● Staying active and trying new things

Helping people to take part in a wide range of activities (old & new, relaxing & active, leisure & work, together & independently) throughout the day is important for people with learning disabilities and/or autism at any time. It enables and empowers them to grow in skills and independence, to become included as valued members of their community and to be able to exercise choice and control in all aspects of their lives. In the context of Active Support, we refer to this as “engagement in meaningful activities and relationships”.

Although important all of the time, it is particularly important in the current circumstances as it:

- gives a sense of achievement, control and purpose
- provides distraction and relief from anxious thoughts and feelings
- provides opportunities for positive interactions and communication
- enables people to make a contribution to the running of the home and help others
- focuses on the present and what we can do, which can help difficult emotions and worries about the future
- ensures people are not left alone or unoccupied (except perhaps by TV) for extended periods of time, as this can lead to increases in behaviour which challenges.

Taking part looks different for different people. For some people it's doing the whole thing, for others it's doing a bit then having a rest. For some it's hours or minutes at a time, for others it's a few seconds. Sometimes people will be the only one involved in an activity at that time; at other times, several people will be working together to do an activity, task or interaction.

With the right kind of support, *everyone* can be actively involved in some way. No one is too 'disabled', too 'challenging', or too 'autistic', to be more engaged and to have more control over

their lives, but to get this right for people with severe or complex needs we need to provide more frequent and skilled support.

● Creating structure and routine

Structure and routine are important to all of us because we don't like uncertainty. It's reassuring when things happen as we expect, when they're in our usual routine, when things feel familiar, when we are confident about what will happen to us, and what we'll do when. We organise ourselves by making lists, writing in diaries, organising our homes so we know where things are when we need them and creating personal routines for carrying out everyday tasks.

Routines help us to organise ourselves and others so we know life is on track and we are in control of things. In these extraordinary times schools, universities and day centres are closed and many people are working from home and we are advised to self-isolate or socially distance ourselves from our friends and family. As a result our normal structure and routine is out of the window. But unstructured time can create boredom and spikes in anxiety or depression and experts consistently advise all of us to keep/establish daily routines at this time. This means eating meals at regular times, sleeping, waking and exercising at set times, and maintaining social (if socially distant) contact.

Structure and routines are even more important for people with learning disabilities and/or autism as they make the world more comprehensible and predictable. Good Structure for people with learning disabilities and autism involves the use of visual timetables, environmental organisation and management, and other non-verbal communication aids to make the world more understandable. Routines help people to understand what is expected of them in specific environments and situations: they can help to reduce anxiety as the person can be confident in knowing what will happen next, how people around them will behave and what they will need to do.

● Active Support

Active Support is a way of providing support which enables people with learning disabilities and/or autism to be engaged in a wide range of meaningful activities and interactions, and empowers people to grow in skills and independence.

It is a person-centred, evidence-based way of working, built on the knowledge that with enough of the right type of help, everyone (no matter how disabled) can take part in all the activities and interactions going on around them and can have more control over their lives.



● Engagement in meaningful activities and relationships

Simply put, engagement means actively taking part – in constructive activities with materials, in social interactions, and in group activities. While you are reading this booklet you are engaged in a constructive activity with materials. If you turn to a work-mate or your partner and say “Look at this - this is interesting” that would be engagement in a social interaction. If you then have a family meeting or team meeting to discuss how you can perhaps help the person you support to be more engaged that would be a group activity.

The video linked below is a montage of photos that show a range of people with different levels of needs and different ages being engaged in a range of activities. It is important to note how it is clear that people are engaged because their hands are on the materials or there is eye contact.



Examples of Engagement: <https://youtu.be/iX68LoP9490>

There will be many things that people do just because they enjoy them or feel relaxed (e.g. having a massage, watching the sunset) or because the activity helps them to feel calm or reduces their anxiety (e.g. using sensory toys, carrying around a familiar or favourite item, or self-stimulatory or repetitive actions such as spinning or pacing or twiddling). Whilst these activities might be important to or for the person (especially in times of uncertainty), they rarely provide opportunities for social inclusion, growing in skills and independence or having choice and control over your life. As such Active Support is about finding a balance between these things that are currently important *to* and *for* people, *and* new things and new opportunities that will improve their quality of life in some way.

Active Support is always about **adding** richness and meaning to people’s lives, never about taking anything away. However, we do find that as we add richness and meaning, people’s reliance on some of these sensory or repetitive activities or behaviours often reduces, as does behaviours which are described as challenging.

Although some people only need encouragement (or sometimes just permission) to get engaged in what is going on around them, many people need substantial help to access these opportunities. There are four key principles of Active Support that can be applied to any activity or interaction to help those who are providing support to work out what they should do in order to help people to be engaged:

Every Moment has Potential – seeing everything that happens at home or in the community (however mundane) as an opportunity

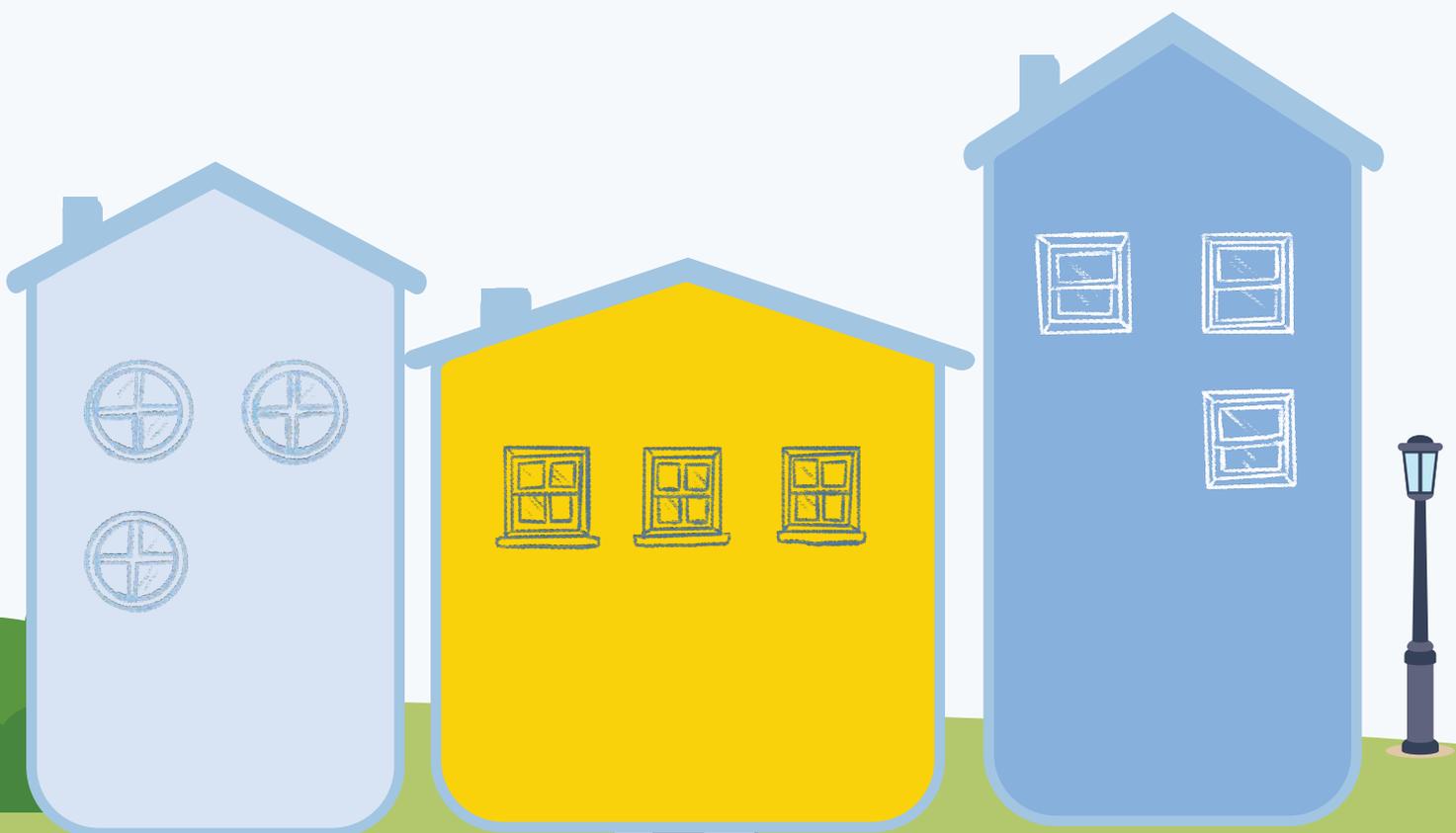
Little and Often – supporting participation in the small parts of each opportunity with slow, quiet, frequent and obvious support

Graded Assistance – providing just enough of the right type of help to enable the person to take part successfully in that activity at that time

Maximising Choice and Control – seeking opportunities for people to make more choices and take more control in when and how they will be engaged

These four principles are underpinned by **Organising and Improving Support**, which focuses on the use of tools and ways of working to develop consistency and predictability for the people being supported, and to encourage ongoing learning and continual improvement of the support provided.

Through this “Stay Inside: Be Inspired” guide and associated resources we aim to help families, carers and support staff understand and use Active Support so that things become more manageable and enjoyable during these challenging times...and beyond.



● Every Moment has Potential

The first element of Active Support encourages us to think differently about activities and interactions and to see the potential opportunities that are available all around us throughout the day. Everything that is happening at home, in the garden and, under normal circumstances, in the community is an opportunity for people:

- to participate
- to try something new or to practice a skill they are developing
- to interact
- to do something with, or even for, someone else
- to make choices and to have control.

Rather than thinking “what could John do today?” Active Support is about thinking “how can John be involved in what is happening right now?”.

Active Support is also a way for us to learn more about the people we support – their likes and dislikes, their preferences for support, what makes them laugh. It provides an opportunity to strengthen the rapport we have with people by trying new things together, learning together, and sometimes getting things wrong together but having fun together.

Historically “community care” has often been thought of as a matter of people being out in the community, taking part in leisure or social activities and for a lucky few, a job. Those providing support have come to value these community-based activities, many of which are disability specific, over and above what they see as the “mundane” activities available around the home. In our experience, many people spend a lot of time waiting for these “valued”, structured or community-based activities to happen.

Whilst such activities can be great and very important to/for people, they sometimes cost quite a lot of money and can't be done at just any time. They are also harder to break down into smaller parts to promote engagement and are more unpredictable and less easy to control – because of bad weather, a supporter being ill etc. Of course, people should be accessing real and inclusive opportunities in the community but our homes, gardens and local neighbourhoods are a tremendous source of activities that are real, need to be done, free, and easy to break down so



that you can do things in small chunks if the person needs this (see *Little and Often*). Whilst lockdown or social distancing means that we cannot access our usual range of activities in the community, it also creates many other opportunities to do things that people might not otherwise get to do. It can also give those providing the support the chance to try new things with people, learn new things about people, develop helpful tools to support people to be as independent as possible and just enjoy the interactions involved.

To put *Every Moment has Potential* into action, we first of all have to get good at identifying all the opportunities available to people and if necessary creating new ones. The video

below provides some illustrations of the many things that people can become involved in and although some might not be possible in the current situation, many are, or can be adapted.



Every Moment has Potential: <https://youtu.be/-ZktZnr6IOI>

Let's think about some potential sources for engagement during this time

1 Household activities

Cleaning, laundry etc.

Well, we could probably argue that there is even more need for cleaning now than ever before! In addition to all the normal opportunities available in and around the house, many people are using this time to "spring clean" – organising, tidying and cleaning their house. Most do it room by room, some cupboard by cupboard... Children and adults can be involved in all aspects of these tasks right down to keeping a record of which cupboards have been cleaned and which ones haven't, just in case we forget.

Many of us are using this time to fix things around the house, redecorate, or at least plan what we are going to do when lockdown is

over. This might also be a source of activity for both children and adults.

Some things need doing more at the minute than usual – people could get involved in disinfecting door handles, doorbells, bin handles and letter boxes (maybe leaving a thank you note for postal workers and refuse collectors)...



Gardening and other outside tasks

Especially as we come through Spring and into early Summer, there are many opportunities in the garden: everything from cutting grass to watering plants to planting and looking after flowers, vegetables and herbs etc., whether in a small container on a patio or balcony or a whole vegetable or flower bed. People can print off and potentially laminate instructions for looking after different plants with photographs and clear instructions so that everyone knows what to do. Maybe now is the time to make some new cushions for the patio furniture – people can get involved in choosing and ordering the fabric, or cutting and sewing it. There's also tidying out the garden shed, cleaning bicycles, washing down the patio, hand washing the car...



Cooking and baking

Now is the time to cook more recipes from scratch – e.g. making the tomato sauce for a lasagne from basic ingredients rather than just using a prepared sauce. Eating healthily is very important at this time so we can get people involved in washing, cutting and cooking more vegetables, making smoothies etc. Now is also potentially a good time to try new foods together and find new recipes. People can get involved in making recipes cards and doing online shopping. You could take pictures of people doing new things and use these to communicate with family and friends (see social activities below). People can make cakes or other goodies to take to the local hospital for NHS staff, to deliver (using social distancing of course) to their neighbours, or to send to their family with a photo or a card...

Some people will be able to plan for a big party when this is all over!



Self-care

Although we don't usually think of it as a household activity, self-care is another source of opportunity. Now is the time to think creatively about what people are not doing that they could potentially get involved in – one example that people usually forget about is managing their medication. There is no reason why, with the right support and checks where appropriate, people cannot be involved in ordering, storing, organising, taking and recording their medication. Similarly people could make sure there is soap in the soap dispensers, or replace toilet rolls in the bathroom etc...



2 Leisure, hobbies and education

Although some children will have been given school work to do, getting them to do it might not be the easiest thing right now, especially if they are feeling very anxious and struggling with the change in their routine. However, sometimes doing homework together can even be fun... especially if you think about how to work the "lesson" into other activities.

For all of us lockdown is an ideal opportunity to develop a new hobby or learn a new skill or language. People might take up sewing or knitting, start doing jigsaw puzzles, learn to play an instrument, sing, take photos while out exercising or around the home and garden, film-making or animation. Photography is one example of something that leads to many more activities - if you take photos you then need to upload them to computer and then decide how to use them – print them, frame the prints, or send them off to be made into things they can give people as presents or sell for an income or charity once lockdown is lifted.

Similarly making artwork, cards, bookmarks, woodwork (bird houses, stools, etc) – not just for the sake of doing it but for things that people can sell to raise money for charity or for

themselves etc. They can be involved in creating a website to display their work, flyers to market things etc.

Even if they are self-isolating due to health conditions, people can still exercise at home – in the garden, in the house, through yoga, aerobics, using the Wii Fit, and dancing, etc. And of course it is also ok for people to just have some quiet time and listen to music, watch their favourite TV programme, play games on the computer etc.

Of course, all of these will be much more fun if you do them together... having fun together is one sure way to build rapport and develop relationships.



3

Contributing to the community and being part of a family or extended network

One of the hardest things about being in lockdown is not being able to see family and friends, especially if you live in a group environment where another person has to self-isolate due to pre-existing health conditions, or because they themselves have the virus. Not everyone will be able to keep in contact using telephone, FaceTime, Skype etc. For some having a socially distanced visit might be possible – e.g. sitting in the garden chatting but adhering to social distancing measures. But for others, this will be too difficult. Making videos, photos, cards or little gifts to send to families and friends (and family and friends doing the same in return) might be one possible way to both keep people actively engaged and feeling connected.

People can also feel connected and be engaged through other activities too. They can contribute to things like making masks and other protective equipment for staff or to send to other places who need them. The house could be a contact point for vulnerable neighbours, and children and adults can be involved in many ways - offering to do shopping or pick up medicines for people and delivering them for example (again adhering to social distancing rules of course).

People could also contribute by putting out people's bins, cleaning their door handles, or looking after their garden, or walking their dog if they can't get out themselves. If none of these are possible people could make little notes and cards to put through older people's doors to cheer them up, or make posters for the

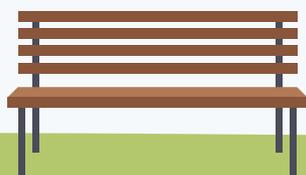


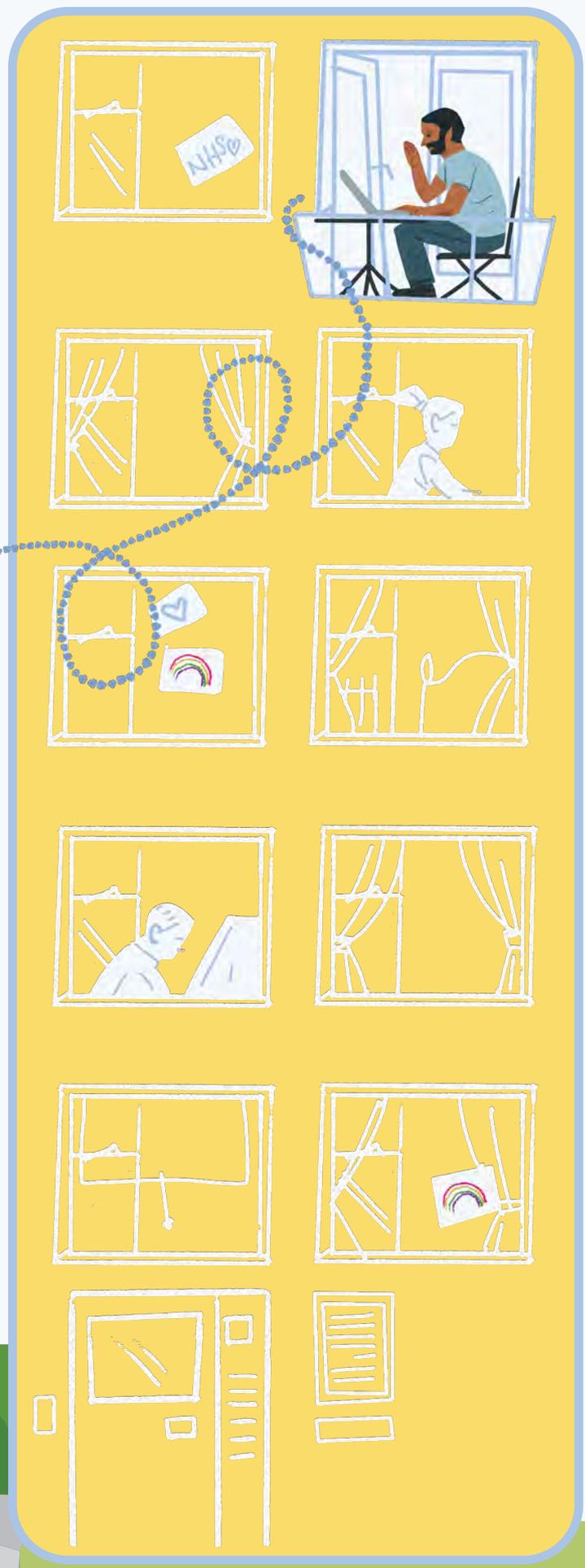
windows to remind people to stay at home, thank keyworkers etc.

People could get involved in raising money for charity or to make up food packages for those who are unemployed, homeless, older, self-isolating, or for health care staff or other keyworkers to pick up after their shifts etc.

Making the most of all the many opportunities available even at home often requires us to think differently – both about the activities and about the person we are supporting. By doing this we can often get more than one person involved at a time.

- In order to see opportunities and help people to participate, we have to see activities and interactions as being made up of **many smaller parts**
- We have to think about the skills, interests and preferences people already have so that we can work out which parts they can do, which parts they need help with and which parts we might have to do, at least for now
- We have to remember that *people don't have to be able or willing to do the whole activity*, task or interaction – they can do just a part of it and still be engaged
- In order to make it possible for people to participate we might need to think creatively and **change when, where and how** a task is done.





● Little and Often

Little and Often is really about making it as easy as possible for people to participate. All of us find it easier to try a new activity when we feel the activity is manageable. We get better at things and build our skills when we do things on a regular basis. When we become more familiar and practiced at something we might be able to do bigger chunks or do something for longer. If we feel we have to do something new or something difficult for a longer period of time we are more likely to find a way not to even start on it. For example, if we walk into the kitchen to see the worktop covered in dishes and the dishwasher full and dishes in the sink, then we are much less likely to start the process of loading the dishwasher and tidying up, especially if we have something else we need to do or if we find it hard to do that task.

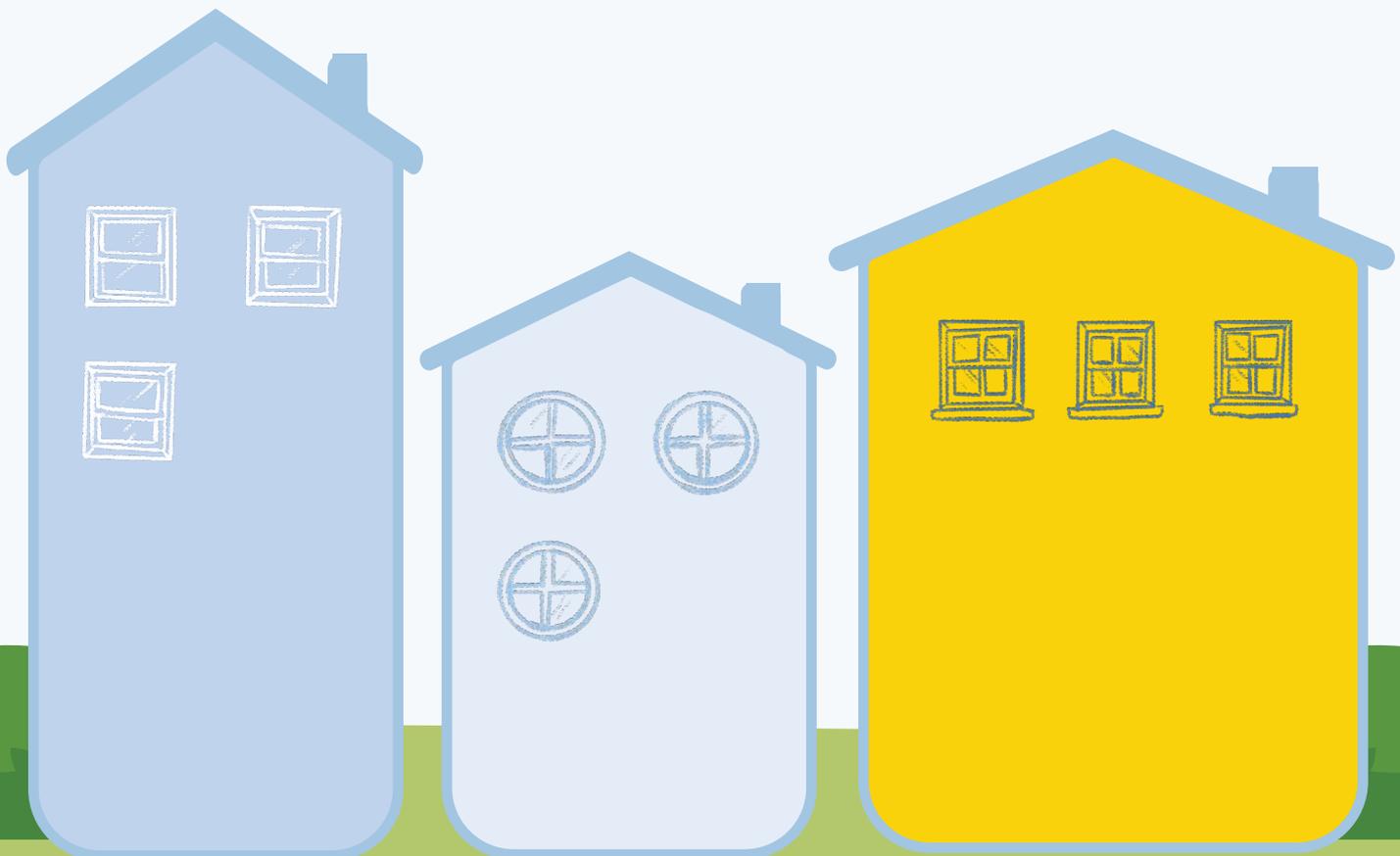
As noted above, engagement can look **different for different people - but it is all GOOD!** Some people can do the whole activity or interaction while others, at least for now, might only be able to do some or very little parts of the activity or interaction. Of course the parts that one person can't do might be something that another person can

do, meaning that it becomes easier to support more than one person to be involved in the same activity, task or interaction. Even if several people are working together, your support may still be needed to bridge the gap between what people can do and successful completion of the activity (or at least the part that needs to be finished right now and can't be left until later).

Some people will be able to stay engaged throughout the activity or interaction but others will need to be able to dip in and out. This means that we need to do things slowly and ensure that there is something left for people to do when they dip back into something. Whilst a few people might initiate and lead the activity, for the most part you will be encouraging and supporting people to join in as active participants.

Make it as easy as possible

In order to help people to get engaged we have to make it as easy as possible for them to get involved. First of all we have to make it as easy as possible for the person to understand what is being offered to them. This involves several things:



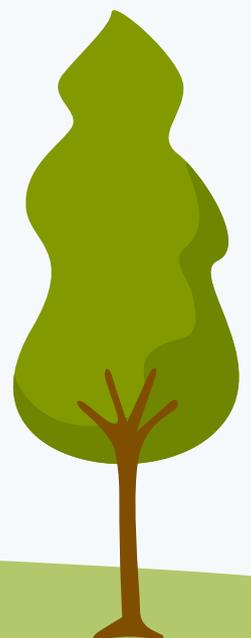
- using the methods of communication that work best for the person and in particular, using visual methods to present both the opportunity and what the person needs to do in order to get started
- making the situation speak for itself by having the materials available so that it is much clearer for people. Remember, people will often have seen materials for most household tasks being used and know what they are for, even if they have never had the chance to use them before.



Secondly we have to make it as easy as possible for the person to do the activity, task or interaction by adapting where, when and how the activity or task is done so that people can do as much as possible.

- if the person cannot reach the kitchen worktop, prepare veg on their wheelchair tray or at the dining room table.
- If people find it easier to do something in a particular order, then adapt the activity so that it can be done their way.
- Share the task with someone else – someone else they live with or the person who is supporting them.

- use equipment and assistive technology to increase engagement and reduce risks. This doesn't necessarily have to be disability specific equipment – sometimes it just means adapting something like a juice bottle as a watering can so that it is easier to hold and doesn't spill everywhere when tipped (as shown in the photo of Phillip below).



Work at the person's pace

Now, more than ever, the phrase “no need to rush applies”. There are fewer external activities to attend so we can slow the pace of what we're doing at home to create more opportunities for people to get involved. And remember you don't have to do tasks all in one go. Let's say tonight's tea is lasagne: people can:

- prepare the vegetables in smaller batches in the morning,
- in the afternoon make the sauce and precook the meat
- an hour before dinner put it all together and put in in the oven.

In fact many tasks have natural breaks built in – e.g. if you make a cake you have to wait for it to cool before icing it. If you are involving the person in cleaning something like the bathroom, you could clean the sink today, the



Supporting more than one person at a time:
www.youtube.com/watch?v=EsFz2NY5P2A



Little and Often: www.youtube.com/watch?v=w_BQG0Y6rWI

mirror tomorrow, the shower the next day etc. You could even get the person to make a checklist (with words or pictures) and tick off each part as it is done. And as mentioned above, where one person might only be able to do a small part and then needs a rest, this gives an opportunity for others to be involved.

For most people we usually say to start small (and build up as the person is ready) – remember it is the person who decides how little they do – if they get engaged at all then that is success even if it is just a little bit today. If they want to do longer or more then we should do our best to facilitate that. *Little and Often* is not about setting a timer and saying “let's do 2 minutes today” ... it is about giving the person control over how much they do once they get engaged – whether that is 2 seconds now and 2 seconds later, 2 minutes, 20 minutes or 2 hours.

● Graded Assistance to ensure success

While we may be making use of the potential of every moment, and doing so little and often, these approaches will not usually be enough on their own to ensure that people can get engaged. We also need to think about the actual help we give them in the moment - the assistance we provide - is it enough...or might it be too much? Is it the sort of help the person needs to be engaged right now? Does the type of assistance they need vary, depending on what we're trying to help them do, and might it change depending on the circumstances? Active Support reminds us to seek answers to these questions through emphasising the importance of graded levels of assistance, which we can describe as:

- ✓ Providing just enough
- ✓ Of the right sort of support
- ✓ To assist this person
- ✓ To be engaged in this activity
- ✓ At this time

It's important to understand that Active Support involves changing - or grading - our support not just to fit the individual, but also to suit the activity and the circumstances; and we should provide enough help to make it a successful experience for them. Clearly not providing enough support won't help the person, but we should also remember that helping too much will limit their opportunities to learn and develop.

So what sorts of support can we choose from?

Words

In most of our relationships with other people we rely on verbal communication to provide them with any help they need from us. We're used to offering words of advice, caution, warning and recommendation; and when we suspect a person hasn't understood, we may decide to "tell them straight". These familiar strategies are ready to hand for us and for some people with learning disabilities and/or autism they work well. Even here though, there is scope for grading our verbal prompts: a question - "where could that flower go?" - or suggestion - "see how it looks on that side" - offer more opportunities for the person, than an instruction - "put that flower there".

However verbal prompts are often too complicated and confusing for most people with learning disabilities to grasp fully. And for others, such as people on the autistic spectrum, language is not only difficult to interpret but also potentially overwhelming. In general if a person doesn't respond to something we've said in the way we're expecting, we should always consider the possibility that they just haven't fully understood the words we've used. Graded levels of assistance are most successful when they include the wide range of non-verbal communication we have at our disposal (but which we don't always recognise): non-verbal communication tends to be simpler to understand, and not to fade like words do as soon as they are spoken.

Showing



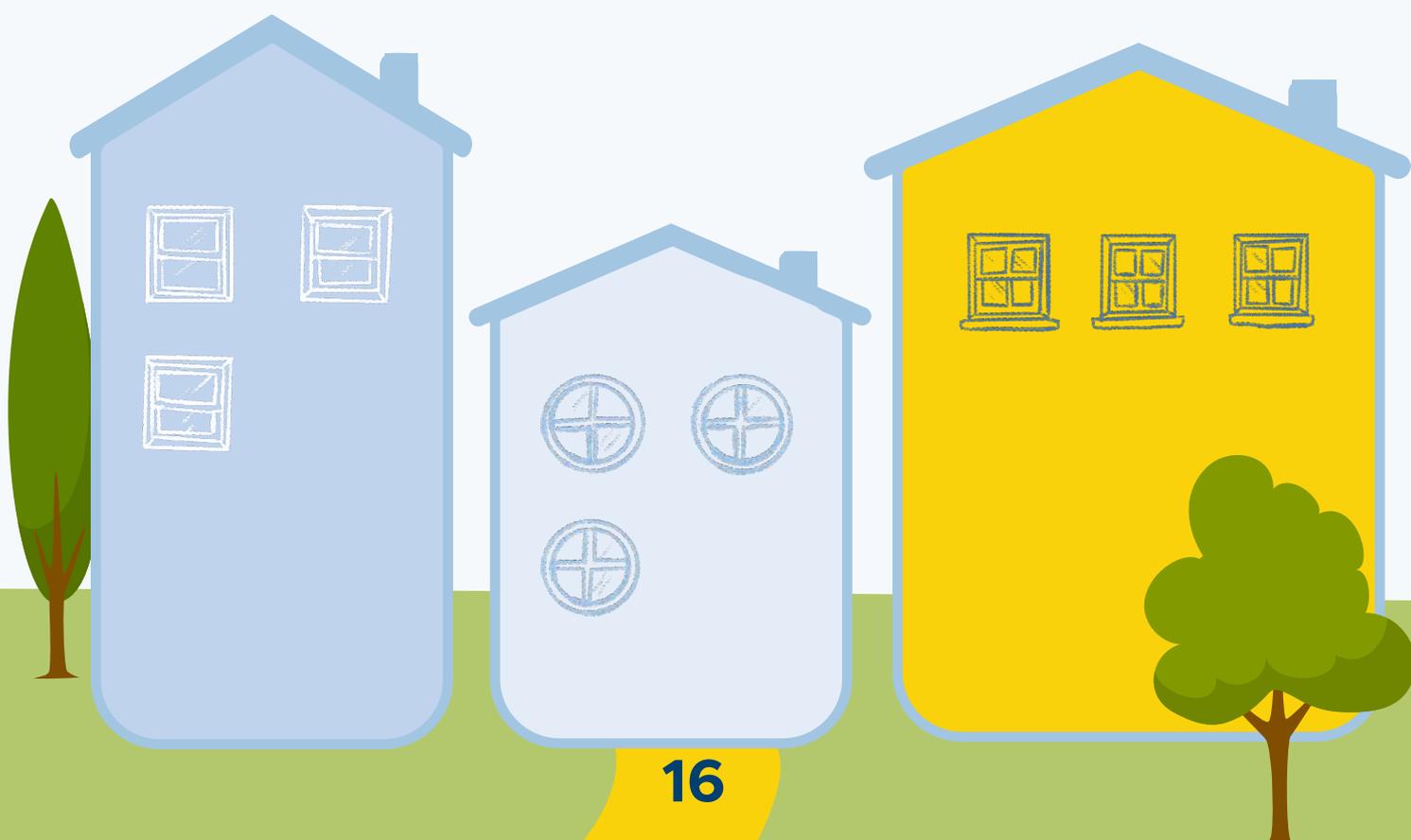
Showing a person what's involved so they can see what they should do is a common example of non-verbal communication that's easier to understand than words. We commonly back up our words with some sort of mime. We might put our thumb to our ear and little finger to our chin to indicate that we want someone to ring us, or that they're wanted on the phone if we're in a noisy place where verbal communication is difficult. This mime is a sort of **modelling** which we can use to make it easier for others to understand what's involved.

Modelling

Modelling shows the person the action they'll need to do themselves: you turn your hand to show them they need to turn a knob; you pick up one of the neighbour's shopping bags to show the person they should pick up the other; you reach up your open hand to model waving. And when we do things together, side-by-side, we have many opportunities to assist a person through modelling because we can be doing the same thing: "you hold the cake and watch the way I squeeze the piping bag ... now I'll hold it while you squeeze".

Writing and Pictures

Sometimes people struggle particularly because words disappear quickly when spoken. Many of us use written lists and reminders and these can be very useful ways of assisting people who have more difficulties in retaining and recalling information. Just because Bernard understands when I remind him of his mother's address doesn't mean he'll remember when he's sending her birthday card: a written template he keeps with his pens will be more useful.



And for people who don't read, pictures do the same job. We can take pictures of recipe instructions and have them in sequence to assist the person's cooking, or line up images of the steps involved in accessing an on-line exercise session. After all, pictures help us all when we're having difficulties understanding written instructions.

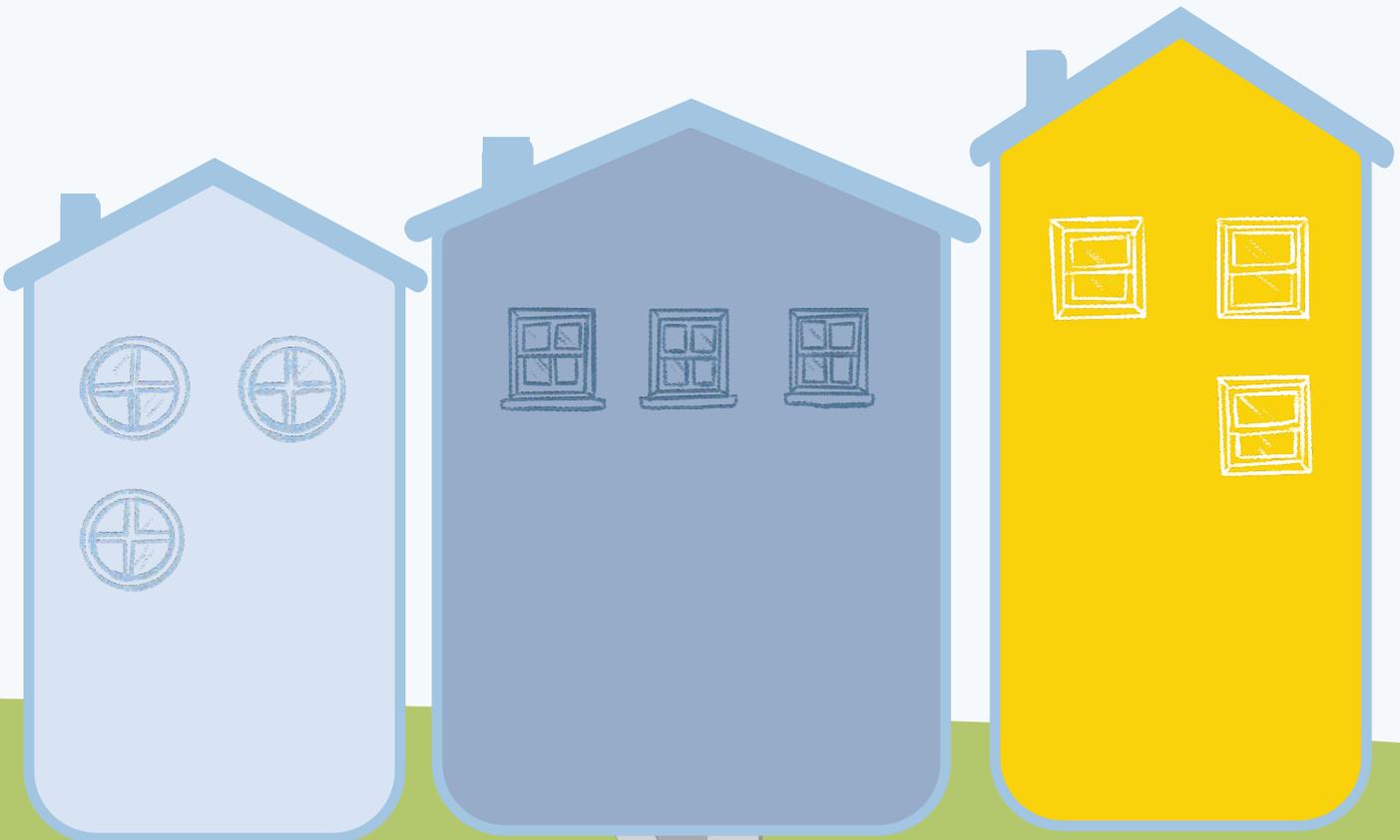


Laying out Materials

Being able to see materials involved helps people understand (or be sure of) what's required. If you can see the things shown in the picture (left) when I start talking about making a ham roll for lunch that's more helpful than an empty table, especially as they are in order from left to right.

Gestures

We use gesture a lot with our hands – pointing at what to focus on, where to put something or the direction to go, or spreading them to indicate the size an object, or how much more of something we need. We don't often realise how much people we're assisting rely on our gestures to interpret what we're communicating so it's always worth making sure the gestures we use are clear – even over-emphasising them as a matter of course.



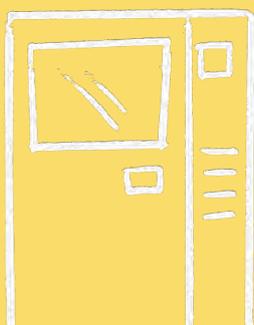
Physical



Most of us need physical guidance from others at some point, and many people with learning disabilities or autism need a lot. When we talk about physical support for engagement we often focus on hand-over-hand support providing necessary direction, stability or confidence. This can be just what a person needs to get involved. But it may not always be comfortable (or indeed tolerable, perhaps because of sensory processing difficulties) for a person you're assisting so alternatives should be considered.



Providing support through another part of the body (such as the wrist in the picture, or the elbow) can be effective physical assistance that reduces or avoids hand contact.





And the object at the centre of the action can become a means of physical support itself, avoiding the need for any direct bodily contact at all. In the photo above the blond lady is holding the plate so that the man with brown hair can wipe it with a tea-towel – but they're not touching each other at all. This **guidance through objects** is often combined with positioning objects to make them easy to access – tipping them or holding them steady – and can be very subtle while ensuring the person is successful – like the person below assisting through just her left forefinger holding the tray steady.

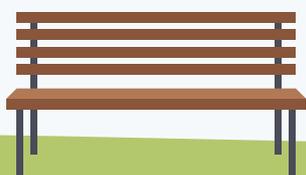


Just enough help

What's important about *Graded Assistance* is its recognition of the sometimes subtle ways we can support individuals to be engaged, as well as highlighting the need to use whatever sort of assistance leads to success, changing it from activity to activity, providing more support (for example adding clearer gestures to words, or using hand-over-hand support when holding the object hasn't been enough) when people need it: if our assistance has failed to support the person to be involved we shouldn't keep repeating it, we should provide more, and more helpful, help.



Graded Assistance: <https://youtu.be/lhmic98tGz8>



● Maximising Choice & Control

While choice is an important part of all our lives, it has to be balanced with the responsibilities we have in domestic life and to others as part of a family or community. We all experience times when we can't choose what we do - but we can have control over when, where, and how we do it. Active Support enables us to provide opportunities and support for people not only to **choose what they do** but also exercise **control over how they do it**.

In order to have real choice we need a number of things. Firstly, we need to understand the choice that is being given to us – both in terms of how it is presented and also in terms of whether we have experience of what is being offered. And secondly we have to have experience of our decisions being respected.

Understanding the choice

In order to get experience to make choices we need to try things and preferably more than once, but in a way that is manageable and does not put us off. We need to use *Little and Often* to build people's experiences so that they can make choices. If we present too many choices or use open choice, e.g. "what would you like to do today", that creates anxiety.

In terms of communication, we need to present choices to people (just like we do opportunities) and support them to select from options, using whatever systems of communication work best for them. However it is almost always helpful for people to be able to see options, even if they understand the words. For some that might just be having the two or three options on the table in front of them – the coffee jar and the box of tea

bags. For others, it might be using photos, drawings or other tools such as illustrated in the images below. The way we need to present choice should match the skills the person has in making a choice.



Decisions are respected

As we noted above it is important that people experience having their decisions respected. If people make a choice but then experience having that choice disrespected or denied in some way, then they will be less likely to make a choice next time the opportunity arises. Of course, there are some situations when we can't just go along with what appears to be someone's choice because it puts them in real danger and we have a duty of care to protect them – if someone appears to be choosing to sit down in the middle of the road, that is not a choice we can respect – we have to persuade them to get up, move to the pavement and then sit down with them.

However, there are many opportunities for choice and control in our everyday routines. There are a number of ways we can maximise them.

Think about standards

There are very few activities that have only one set way to do them. How we do them is not necessarily the only or right way! It is our preferred way. But sometimes people don't experience choice or control because the standards or values (of those supporting them) get in the way; consider the example in the sidebar.

Plan

We find that often those providing support don't intend to disrespect people's choice but through lack of forward planning or preparation this is how it can seem to the person. This could be for example, by offering a choice of two activities, letting the person make a choice and then realising that there isn't enough time to do the activity the person chose, or you don't have the right ingredients or materials needed.

Respond to requests

We can also give control (just like independence) through how we support people especially when they need physical guidance. Ensuring that people can indicate when they want to stop or have a break, by for example removing their hand or drawing their arm back, is important. If we hold them too tight or provide hand-over-hand guidance when this is not needed, then we reduce the ability for people to have control over how long they do something.

Think about the following example of allowing someone control over **how** to do something:

You are supporting someone to make their bed and you open the linen cupboard and point to the pile of fitted sheets and they choose a pink sheet. You then point to the pile of pillow cases and they choose a red one. You wait a bit and then look at the duvet covers and they choose an orange one.

What should we do here? Well of course we should help the person to make their bed using the linen they have chosen. But how many of us would have been tempted to change the linen so that it matched, feeling that this was the "proper" way to make a bed? Does it really matter if the sheets don't match? Is it a health and safety risk? Will it stop the person sleeping? This is exactly the type of control that we can easily give people but often miss.

Encourage independence



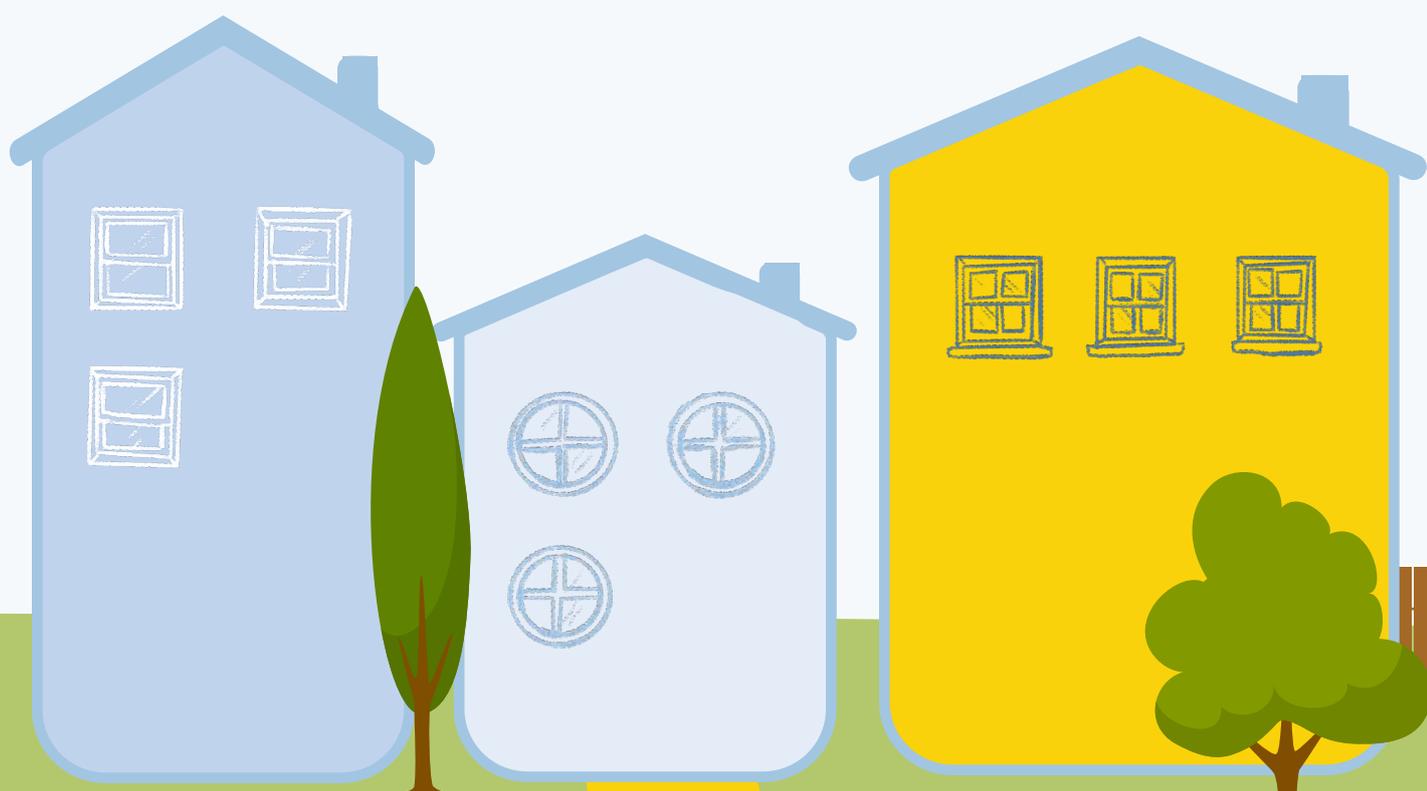
Choice & Control: <https://youtu.be/gBeEcZ2SK28>

Enabling people to do things as independently as possible – e.g. serve their food at the table – also gives them control over how much to take (accepting that sometimes some people may need help to take enough but not too much food, but we can manage that by ensuring that we don't put too much on the table in the first place). By working at the pace of the individual, we can give them control over when or how fast they do something. Using visual structure in the environment and organising the environment so that the child or the adult can find the things they need when they need them, without asking for help, not only builds independence but also allows them to have control.

Managing risk

Normally we spend more time talking to staff and families about how to see beyond risk and to ensure they are engaging in positive risk taking and managing rather than avoiding risk! However, these are exceptional circumstances and managing risk both in terms of exposure to COVID-19 and in terms of keeping people well and free from injury more generally so that they don't need to seek medical treatment is important.

We are working on the principle of balance - we need to find an effective balance between giving people the opportunities and support to be engaged and try new things so that they can build up their experiences, learn new skills and have choice and control AND balancing any risk to the person and others. However, as we discussed under *Little and Often*, there will almost always be opportunities for people to get safely involved in almost everything that is going on if the four principles are applied.



● Organising and Improving Support

Active Support requires some organisation and planning, and it's most helpful when those involved learn from each other's experiences. In these times of uncertainty, *Organising and Improving Support* also brings predictability and consistency, reducing anxiety through reassuring familiarity.

Predictability and Consistency

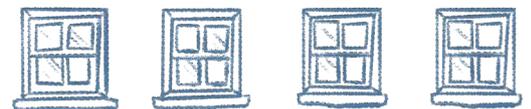
We all need to be able to predict what's happening around us, if we are to engage with it. Most of us achieve the levels of predictability we need through successful experiences and by following our own routines. As we discussed earlier, those routines have been severely disrupted by the response to Covid-19. For some this will have led into new but unhelpful routines: getting up late, not getting dressed, watching a lot of TV and eating and drinking more, and more frequently.

To avoid this for people with learning disabilities and/or autism we should use the four elements of Active Support to develop new opportunities at home, and then plan how to arrange them into a replacement predictable, consistent and helpful routine. If things have already fallen into an unhelpful routine, we will need to plan a gradual introduction, and increase, of these new opportunities into that pattern – it will take time and persistence.

The unfamiliar nature of the lockdown means that most of us are anxious – and this makes the reassurance of routine all the more important. Some people with a learning disability and/or autism will be reassuring themselves through increased repetition – of behaviour or speech – we might be calling

these compulsions, obsessions or self-stimulatory behaviour. The routine we develop will need to accommodate whatever ways of coping with anxiety people use (like with Peter in the example below), at least until our new routine begins to provide the reassurance they need.

When Peter is tired at the end of the day it happens quickly and he really needs to go to bed straight away. But now he won't sleep if he hasn't checked all the outside doors, so if he's tired and hasn't checked the doors, he quickly becomes anxious and frustrated as he races round the house, shouting about security. His routine needs to allow time for Peter to check the doors, before he hits that sudden overwhelming feeling of tiredness. And if there are other things Peter's worried about, this becomes even more of a necessity.



Good routines

Good routines include activities and rituals that are important to the person – things they enjoy or need, happening in ways they understand. They also take account of what other people involved need – and this should include time-out for those supporting a person: time to recover strength, or do something else, or just time for themselves. This is easier to achieve in service settings where staff work for limited periods at a time, but often needs specific planning in family settings.

Good routines are also flexible and have contingency plans built in. We know all too well that the unexpected can happen – especially in our current circumstances! Good routines allow us to take advantage of opportunities we haven't anticipated, or deal with delays or other demands, but remain the plan to which we return in due course. Good routines are not fixed, inflexible or institutional. Neither are they unchanging. They should change to reflect time of year and cultural celebration, although they may need to change less dramatically for some people. Good routines are a key part of providing effective structure. Getting good at structure means we not only sequence events and activity reliably, but also communicate what is happening (and will happen) through supportive visual information like timetables, non-verbal communication and the way the environment is laid out.

For more information see this handy guide to Structure: <https://bit.ly/2TgysqN>

Learning and working together

Structure should change as a result of what we learn – about what activities work, when, where, how, in what order, at what pace and with whom. Sharing this knowledge, built

in the light of experience, is one of the ways in which we develop consistency across a number of people providing support. Without that sharing (and agreement to be consistent) those providing support are asking the person to adapt to their differences – at a time when they're already needing to cope with too much confusion and change.

In services where a range of people are providing support, predictability and consistency usually require a written plan of who's going to do what and with whom – sometimes called a shift plan – as well as formal opportunities to discuss and record ways of helping staff provide effective structure consistently.

See this guide for more information about developing effective shift plans: <https://bit.ly/ShiftPlanGuide>

In family settings such issues are usually better understood. But everyone involved in supporting a person will need to work out how much consistency they actually need, because this is individual: just enough consistency is what's required. You may like this video explaining how much is enough:



What We Mean by Consistency: <https://youtu.be/MlsvuzL8nq8>

Visual Support

We explored the importance of visual information in *Graded Levels of Assistance*, and it's worth further consideration here. This principle applies to organising support too. The more visual back-up we can give our structure – especially when we're in unfamiliar times and anxiety is high - the more helpful it will be. We know this is true for ourselves: we agree to ring our friend on Monday evening, but over the weekend begin to doubt whether we've remembered right; however we thought to write it in the diary and can go back, check, and be reassured. The visual information we've created is permanent, reliable and reassuring, and will still be there if we become uncertain again.

So for people with learning disabilities or autism, who experience greater difficulties in processing, keeping in mind, and recalling information when required, visual support plays a vital role in reinforcing the reassuring benefits of structure. What sort of visual information is helpful clearly varies from person to person, but the range of possibilities is wide: from lists on the fridge and careful use of a family planner, to visual timetables and picture cards showing what's happening now and next; and from text reminders and iPad alarms, to picture recipe books and photo reminders of the sequence of handwashing. The critical issue is that the information is accessible, ie both understandable and available, to the person.



It's almost always a good idea to have a visual timetable that shows information about what's happening when. It should be somewhere easy to see, and be in a form that is easy to understand. Watch this video from Jill Bradshaw for more details



Visual Timetables: https://youtu.be/wnqu_ttnRO8

Learning as we go

We're all learning how to cope in these unusual circumstances, doing things we've never done, nor thought we ever would. Those supporting people with a learning disability and/or autism can help them by supporting engagement and creating structure and routine, as well as keeping them safe, within these new and confined arrangements. Learning how to organise and improve our support will enable us to be inspired during our enforced stay at home.

● Resources

More Stay Inside: Be Inspired resources

Introduction to Active Support webinar

– this is an opportunity for you to listen to a talk about Active Support based on this booklet, with the opportunity to ask some general questions.

Having a go webinars – these will allow you to think about using some of the principles and guiding you through some practice exercises and providing an opportunity for questions and answers. There will be one for families and one for staff working in services. Further webinars will be provided on specific elements of active support if there is sufficient demand.

Webpage: www.unitedresponse.org.uk/stay-inside-be-inspired

Facebook group – we have set up a Facebook page where we will post new resources as they emerge and also where you can ask questions of a range of academics and practitioners working in the area of Active Support. Find us at:

www.facebook.com/groups/stayinsidebeinspired/

Link to suite of other United Response practice resources

You can find other related resources on our website:

www.unitedresponse.org.uk/support-guides

Video resources

You can find a large range of videos illustrating different elements of Active Support and other elements of good support on United Response Practice Development You Tube Channel:

www.youtube.com/playlist?list=UUoSf_7hfkYe3yyTa_1KcXA

More resources on Active Support

You can learn about Active Support in more detail, through our self-study guide:

bit.ly/PavilionActiveSupportHandbook

We also have a resource for those who have some experience and who would like to train others such as their staff team:

bit.ly/PavilionActiveSupportTrainingPack

Information about COVID-19

There are many websites provided resources related to COVID-19 but we have found that one of the best is the Social Care Institute of Excellence which has brought together many different resources for care staff, for parents and carers and for social workers and occupational therapists. This includes easy read resources for helping people to understand about COVID-19 and why we have to stay inside. See:

bit.ly/SCIECovid19Guides



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