A person-centred Christmas

A practice development guide





Many people with learning disabilities, autism or mental health needs struggle to enjoy Christmas as much as they could, due to disrupted routines, sensory overload, social expectations and crowded places.

This guide describes strategies and tools to use with families, friends or support workers to work towards the best possible Christmas.



Introduction

Christmas has become a massive annual festival – "it's the most wonderful time of year" – that affects everyday life more, and for longer, than any other religious or cultural event. For many, the light and comfort of Christmas provides a welcome means of coping with the dark and cold of winter; for others it provides a reliable opportunity to socialise with family and friends and a break that marks the turn of the seasons towards the New Year and longer, warmer, days

Everyone has the right to enjoy this time of year but not everyone can, or wants to, cope with the ways they're "supposed" to enjoy Christmas. Our festive season comes with expectations attached: to enjoy glittering lights and crowded markets; to relish a morning of surprises hidden in brightly coloured paper; to relax into different routines (or no routine); to welcome unexpected invasions of guests and substantial changes to the look and feel of the environment at home and elsewhere. Christmas also has particular associations with specific religious and cultural traditions: people who don't share such beliefs or heritage often find it difficult to participate in a communal festival they might otherwise welcome.

The changes that come with Christmas, and our shared expectations about it, can also make it difficult for people with a learning disability, autism or mental health needs to cope with, never mind enjoy, the time of year. The disruption to structure – in routine and in the environment – combined with the potential for sensory and arousal overload can lead to escalating levels of anxiety and distress, which may in turn precipitate behaviours that challenge.

Our approach in any circumstance involving behaviours that challenge will always be Positive

Behaviour Support, and therefore will address the setting conditions, triggers and consequences associated with the behaviour, not deprive the person of opportunities to maintain and enhance their quality of life, nor resort to restrictive interventions without fully exploring other, more humane, support.



► This guide brings together a range of strategies and approaches that support workers and families should consider when they support a person for whom "it's the most difficult time of the year". You can reduce the difficulties by ensuring Christmas is what the person wants, not what others (including you) think they should want.

Early Preparation

The most helpful way to address Christmas-time difficulties is to anticipate them, and plan ahead. Christmas decorations start to appear in the shops in September, high street lighting displays are switched on in November, discussions about who's going where on the day start in October, etc. So anticipating difficulties is best done early.

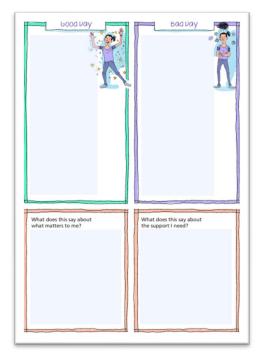
• Find out from the person as much as you can about what they like about Christmas, and what they don't like, so that you can plan what's going to work best for them.

You can use the <u>Good Day/Bad Day tool</u> to record what the person says about the day itself and the <u>Coping Strategies tool</u> to record for the period before and after Christmas. Use these tools to record things like the preferred order of activities, what the person likes about the season, what needs to happen to ensure it is a good day.

• Talk to the person's family and any long-term friends. Ask about what the person will expect to happen: what have they experienced in the past? What strategies have been used previously to reduce any anxiety and distress? When do they start talking to the person about Christmas? Is that a good time for you to do the same?

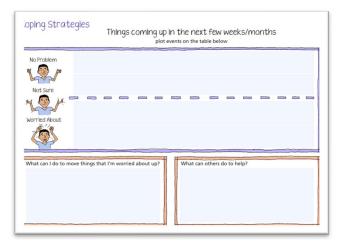
If the person is not going to be celebrating Christmas, or isn't able or willing to join others to do so, plan alternative ways for them to spend the day – look for activities they can join, or places that will be open on the day (eg. Indian Restaurants usually are), or activities they like that wouldn't usually be considered festive (like an all day hike) which will suit them.

 If the person has lost family members and longstanding traditions, plan new traditions for a future way of doing Christmas.



The Good Day/Bad Day tool

► Free template download



The Coping Strategies tool

► Free template download



Early Preparation (cont.)

- Think about what communication support the person will need as the festive season approaches and what will take to get them in place in time?
- Plan ahead to replace activities that might not be possible because of bank holidays or other Christmas closures. Think about ways to adapt activities rather than have them not happen at all.
- Find out who will be expecting to visit the person agree a plan that will help, e.g. staggering visits so that the person is not faced with too many people at once, perhaps over a number of different days.

"Roy's mother told us he doesn't like a Christmas Dinner and prefers a plate of ham and cheese sandwiches and a packet of crisps on Christmas Day.

I had to really stop myself from bursting out with 'But that's not a proper Christmas Dinner'"

- Find out about quieter times in supermarkets (some have autism or sensory friendly, or quiet times with no music or tannoy announcements and with the annoying self-service tills turned off).
- Plan alternative routes for transport to allow for busier roads and public transport – particularly if the person you support finds waiting and delays difficult.
- Think about the extra stress of being in crowded areas at Christmas, e.g. the difficulties of pushing or self-propelling wheelchairs through crowded areas. Allow more time for going slower or having a rest, or not being able to find a free table in the café book ahead if you can. Buses are more like to be full, so organise a taxi instead.
- Plan for after Christmas arrange pleasurable activities for the times that follow.



In the lead up to Christmas

Think about what's going to work best in the time when Christmas is anticipated, but not here yet – and remember this can be for some months!

- Consider a calendar countdown (<u>like this one from Autism NI</u>) so the person can see days and events that will happen before Christmas. Use pictures of people, places and events to mark out the days. Support the person to cross them off. if that works. Include their own Christmas preparations (like when any decorations will go up, the days for buying presents or for posting cards etc.) and other non-Christmas events and activities that the person knows about and can use to understand the passage of time.
- As it gets closer, think about using a bigger visual timetable with more space available to show events yet to happen in more detail. Use the same for the festive period so it's clear what will happen when.

"We'd developed a really good routine with Bill that involved going to a particular shop every day.

But it closes for two weeks at Christmas, so we had to plan an alternative shop. We used a social story to explain it to him and he was fine, much more so than if we'd just abandoned the routine for that time."



- Think about ways of keeping a person's routine the same, or similar over the festive period.
- Start to use contingency plans for travel to avoid crowds and delays.
- Consider a gradual change to the physical environment, adding any decorations a bit at a time so people can get used to them, or putting the tree up undecorated for a few days before adding to it. Find ways to support everyone to play a part in this change it's usually helpful to avoid the sudden and extreme change involved in the traditional way of putting up decorations. For some people, it's will be important to be in control of this adjustment of their environment.





In the lead up to Christmas (cont.)

- Think about preserving some undecorated areas of the house 'Christmas-free zones'. Or leave most of the house undecorated and have a Christmas zone. Or leave passages, landings and hallways free as pathways or refuges.
- Think carefully about the settings on lights some may seem fun to you but may be painfully overstimulating to people you support.
- Be aware of other sensory overloading that people might experience – the unusual smell of a tree in the house or candles, musical cards etc.
- Consider giving, receiving and unwrapping presents over a longer period than just Christmas Day, or agreeing in advance to only have a small number of presents on the day itself.

- Think about making presents not about surprises tell the person what's in them, use see-through wrapping paper, or don't wrap them.
- Consider agreeing not to watch the person while they unwrap a present.
- Think about crackers. You can take them apart in advance to remove the bang or to substitute a more suitable gift inside and then put them back together ready for the day. Or you can make them with the person so they know what to expect.
- Plan the day what's the order things will happen? Will there be periods of downtime? Are there important key moments? What's the plan for meals will everyone eat together, or will there be ways for people to be part of the meal but not overwhelmed by sitting around a big table with others? Do some people just need to take their meal elsewhere?
- Consider planning downtime before and after specific parts of the day.
- Think about creative alternative ways people can be involved but not troubled.
- Use photos of previous Christmases, photos of who will visit and who will be on duty, where the person will go to, etc. Talk about what's going to happen.



Christmas Time

You've planned it well - now it's here!

- Put the plans for the festive period into action.
- Remember your aim is to create a person centred Christmas, not anybody else's expectation of what Christmas should look like – and it doesn't have to be the "best Christmas ever"!
- Give people ways to control the speed at which things happen, or to change the plan in ways that will help them cope once the day is under way.
- Give people control where possible over things that make them feel comfortable, e.g. if the person wants to go first with handing out presents so they know when it's them, and there's no waiting and uncertainty that's probably better than trying to make it so everybody gets a turn.

"I used to support a lady who liked receiving presents, but didn't like the whole "opening presents together" thing.

She loved walking so we made it into a two-hour treasure hunt walk"

After Christmas

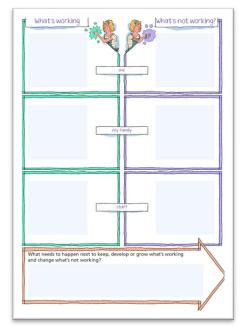
After months of build-up leading to the big day, Christmas suddenly comes to an end – everything to do with it stops or disappears.

Again the issue is our collective expectation, and it can be very difficult for people to adjust to this sort of abrupt change and the end of all that anticipation and excitement – all at a time of year that's famous for miserable weather and grim short days.

So consider some strategies that smooth out this sudden let down

- Take decorations down gradually.
- Plan pleasurable activities to shift to after Christmas.
- Maintain a Christmas area in the house for some weeks after the event.

- Use the same visual timetable and countdown approach to forthcoming events and activities.
- Even if you don't prolong Christmas into January, have a visual timetable that shows when different things will go away/come down etc.
- If a person has been away from home for some of the festive period but needs to be part of taking down the decorations, save some for them to do.
- If it works best to take all the decorations down on Christmas night, then do that rather than trying to hold out until the traditional time.
- Think about what's worked this year and what's not worked. Use this <u>Working/ Not Working tool</u> to record and plan for a more enjoyable festive season next year and beyond.



The Working/ Not Working tool

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Other Resources

- A webinar in which members of the United Response Practice Development team discuss some of the issues raised in this guide is <u>available now on YouTube</u>.
- The National Autistic Society have <u>published some great</u>
 <u>Christmas tips</u> for autistic people and their families
- Other useful United Response resources include:
 - Foundations of Good Support Structure
 - Foundations of Good Support Communication
 - YouTube Lots of

Lots of useful videos on Active Support, Structure and Communication are available on the United Response Practice Development YouTube channel

Graphics by Jonathan Grey-Wilson (www.grey-wilson.com)
Photographs from istock (www.iStock.com)
Coping Strategies tool developed by the NDTi Preparing for Adulthood Programme (www.preparingforadulthood.org.uk)



