

HAPPY HOLIDAYS

A GUIDE TO SUN, SEA AND
SPECIALIST EQUIPMENT

PLANNING TIME AWAY WITH CHILDREN, NO MATTER HOW LOCAL OR DISTANT, CAN LEAD TO A LOT OF FUN DURING THE JOURNEY AND ON ARRIVAL AT YOUR DESTINATION. HOWEVER, WHEN A CHILD HAS A DISABILITY THE PLANNING AND ARRANGEMENTS TO ADAPT JOURNEYS AND THE TIME SPENT AT THE LOCATION CAN BE VERY STRESSFUL FOR FAMILIES.

THROUGH LISTENING TO PARENTS WHO HAVE CALLED OUR NURSE HELPLINE WE KNOW THAT FAMILIES ARE STRUGGLING TO GET THEIR CHILD'S DAILY NEEDS MET, YET ALONE HAVING THE TIME AND ENERGY TO BE ABLE TO ASPIRE FOR ADVENTURES – BUT WE PLAN TO CHANGE THIS BY OFFERING A GUIDE THAT HIGHLIGHTS PRACTICAL AND EMOTIONAL CONSIDERATIONS SO THAT DAYS OUT AND HOLIDAYS BECOME FUN AGAIN.

If you would like to speak to Newlife's Care Services Team about anything in this brochure call **0800 902 0095** (free from UK mobiles and landlines) or dial **01543 468 400** (normal call charges apply) Monday – Friday, 10am – 4pm.

Alternatively you can email:
nurse@newlifecharity.co.uk

Please note that verbal translation services are available through the Nurse Helpline.

Need support or information?



Want to speak with a Newlife Nurse?

Newlife's Care Services Team readily use confidential translation services. We want you to feel comfortable when raising sensitive questions or discussing important matters.

 **0800 902 0095**

Simply call (free from UK mobiles and landlines) and inform a Nurse of your preferred language.

Newlife Nurses will provide caring emotional support and useful information regarding:

- rare & complex conditions;
- local & national services;
- rights & benefits;
- access to health & social care professionals;
- delivery of care in the community.

PLANNING YOUR HOLIDAY

Timing is everything. You may need to be in the right frame of mind to even start considering leaving your home, and given the recent travel restrictions imposed because of the pandemic and the potential risks to the health of your family – please know that you are not alone when feeling reluctant to leave the convenience and safety of your home!

How much will the adventure cost? Plan ahead and consider the cost of a return journey, the cost of visiting attractions, and the cost of an overnight stay with arrangements for eating out. An adventure can be as cheap or expensive as you want, but forward planning for meals and booking accommodation in advance can save a lot of money. Only you can determine if the cost of visiting an attraction is worthwhile, and remember that there are always hidden costs - so ensure you factor in a contingency budget for additional extras that may not seem essential until you arrive.

You may find it helpful to consider small ventures out into your local community and local areas before building up to a longer journey and destination further afield. Why not plan a day out at a nearby visitor attraction with an overnight stay near to your home so that you can prove to yourself that meeting your child's needs and sleeping in an unfamiliar setting can work? You could stay at the home of a friend or family member rather than a hotel, and you have the security of being able to return if arrangements do not go to plan. Once you know this, you will be in a better position to think about longer stays in places further from your home.

ACCESSIBILITY

Accessibility is extremely important when planning to leave your home for any period of time because you will need to ensure that there are disability facilities in the form of dropped pavements and even surfaces, access to public transport, accessible public toilets (you may need a RADAR key), quieter environments so that sensory needs are met, and more. It can be useful to read reviews, but bear in mind that what works for someone else may not work for you. You should make a list of your child's needs in terms of access, sleeping arrangements and toilet facilities when planning where to stay. This might include things like:

- a ground floor room or lift access;
- wide doorways;
- raised toilet seats;
- wheel-in showers and space to use and store portable equipment;
- the height of the bed;
- a quieter room away from traffic noise;
- good lighting;
- power sockets to charge devices.



Expect there to be unexpected situations, and recognise that this may not be because of an oversight you made when planning.

Talking with your child and asking them to tell you where they would like to go or help them to draw a picture of the places they would like to visit, or activities they would like to do, may help identify what kind of adventure your child is ready for – you can then identify ways to transition to being able to do this. For instance, if your child wants to go to a beach in the UK but you find it difficult to plan a journey just to the supermarket, include them in the journey to the supermarket to buy an inflatable beach ball, a new outfit for the day out, or sun cream (being mindful of allergies and sensitivities) - buying non-perishable items means that you can pace the trip for a time that suits you.

Plan some time for yourself. Some personal time can make a world of difference when mentally preparing yourself to do something that doesn't come easy or hasn't been done in a long time. Why not use your transport of choice for your future trip or go for a leisurely

peaceful walk somewhere you have never been? It will start to build up your tolerance for new experiences and remind you that there is more to you than your role as a parent and carer.

You don't have to do this alone. Why not make plans with extended family or friends who can help make arrangements and share in the joy when you overcome perceived and real barriers? Choose people who can empower you to make plans rather than take the planning from you, but also those loved ones who can help meet your child's practical needs and your emotional needs.

No matter how much you plan, and how much support you have, you should expect that some of the arrangements will go awry and either the timing of your journey or plans when you arrive will need to be reconsidered in the moment. This is why understanding all of your options during the planning stage of your trip is really important, but also trying to adopt a 'c'est la vie' attitude so it doesn't cause too much upset. Expect there to be unexpected situations, and recognise that this may not be because of an oversight you made when planning.



Do you need inspiration of where to go?

There are some really fantastic online resources that are designed to help you plan your adventure, no matter how adventurous you are feeling and what your travel and accommodation needs look like. We have collated a list of websites here to help inspire your next trip.

Staying close to home:

- [National Autistic Society](#) has ideas for holidays and days out in the UK. They also have information on Autism friendly cinema screenings.
- [The Calvert Trust](#) may be able to help provide access to outdoor activities. Wheels for Wellbeing support disabled people of all ages and abilities to enjoy the benefits of cycling.
- [The Council for Disabled Children](#) could offer some new ideas for joining in with group activities, particularly for older children.
- [Day Out With The Kids](#) has a very useful search engine to find new ideas for days out.

Travelling further afield:

- [Family Holiday Association](#) can fund short breaks, group trips and days out, while providing practical information and fun family resources.
- [Rough Guide to Accessible Britain](#) is a free downloadable guide that has fantastic information on accessible days out in Britain.
- This [website](#) has information on how to contact/find tourist information centres in the UK.

The following websites provide guides to visiting beaches that are accessible for all:

- [Tourism For All](#)
- [The Accessible Planet](#)

The following websites provide assistance with finding accessible accommodation:

- [Enable Holidays](#)
- [Sebastian's Action Trust](#)
- [Disabled Holidays](#)
- [Visit England](#)

Taking your home with you - Caravanning and Camping:

Some people may find it easier to be independent if the items they need are self-contained in a home away from home, in the form of a tent or caravan – and this may help feel more confident for travelling further afield. There are some helpful resources here that you could reference in order to consider this option:

- [The Caravan and Motorhome Club](#)
- [The Camping and Caravanning Club](#)
- [Pitch Up](#) has information on campsites with facilities for disabled people.

HINTS & TIPS

Researching activities and places to visit can be done on the internet – this will allow children to see pictures and videos of what they can expect and help manage expectations, give you the opportunity to check opening and closing times for the venue or attraction, check the location of car parks or proximity to public transport and how much it will cost to get there, in addition to whether there are accessible toilets. You may want to consider getting a RADAR key to enable access to disabled toilets. Contact your **Local Authority** or [Disability Rights](#) for further information.

Do the venues/attractions offer concessions or additional arrangements for people with a disability and their carers?

- Take a look at theme park websites. Many offer a free carer place to support a disabled child. Many also provide a 'pass' to cut through queues!
- [The CEA Card](#) is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA). The card enables a disabled cinema guest to receive a complementary ticket for someone to go with them when they visit a participating cinema.
- Quiet hours in shops (also known as an autism hour) – is a specified time when shops turn down anything that makes any noise in the venue and remain mindful of this during this specified period. You should contact the individual shop to determine the arrangements made for people with additional sensory needs (as these may vary according to seasonality and planned instore events) but you can find more information at [Enable Magazine](#).
- [Blue Badge Company](#) provides information on entertainment and travel discounts for disabled people.
- [Money Helper](#) has a wide range of information about financial savings.
- [Disability Grants](#) has information on discounted days out that could be helpful.
- [The National Trust](#) has a very useful guide to the facilities available to visitors and the National Trust Essential Companion Card enables free access to a carer.
- The [English Heritage](#) website explains that you can bring a companion or helper for free. Just select an 'Essential companion' ticket when you book for your companion. You should check the webpages of each individual property/attraction for more information about accessibility.

PLANNING YOUR JOURNEY

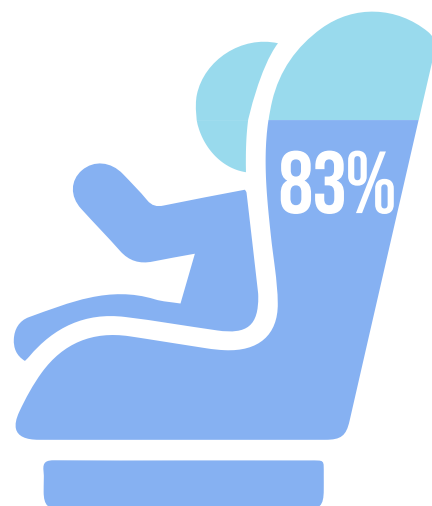
In addition to normal considerations - such as the route of the journey and how to avoid traffic, the duration of the journey and what time to set off, the best place to stop for a break, and how to entertain the kids during the journey – the planning of a journey can be much more complicated for parents of children with disabilities. Below are a series of equipment and medical considerations that may help you to plan your journey and what you'll need during and when you arrive.

Equipment Considerations:

In addition to the informative support available on Newlife's Nurse Helpline that may help overcome some barriers to your next adventure, you may want to plan ahead and seek funding for equipment from local health and social care services. You may also want to consider approaching charitable organisations – particularly if equipment has already been provided and remains useful to your child as the statutory services will tend not to provide duplicate types of equipment for use in different settings, especially when the equipment is transportable, no matter how inconvenient. Newlife's **Equipment Grants** are available for essential community equipment, but may take some time to commit funding, and this does very much depend on the individual circumstances detailed within the equipment application.

Do you need a specialist car seat?

Supportive seating is incredibly important in all situations, and too often car seats are overlooked as playing a large part in the management of your child's posture. If not seated correctly, a child's protection in the case of a car accident may be compromised, but equally if there isn't enough postural support then there can be a deterioration in a child's health during a journey because of unevenly distributed weight. In 2018, 83% of local authorities across England had an unlawful blanket ban on the assessment and provision of car seats. Since then we have challenged, and continue to advocate for, changes to restrictive policies, and more information can be found [here](#) about which local authorities will now consider committing funds to purchase a specialist car seat.



Will you need a mobile hoist?

Local social care services will tend to provide ceiling tracked hoisting for use within the family home and this will satisfy their statutory responsibilities for safe manual handling, and as such if you will need access to a mobile hoist then you will probably need to seek charitable funding or consider purchasing it yourself. Organisations (in addition to Newlife) that may consider providing funds for a mobile hoist include:

- [Children Today](#)
- [Independence at Home](#)
- [My AFK](#)



Do you need to take a wheelchair/buggy and/or standing/walking frame?

Local wheelchair services can assess and provide specialist wheelchairs and buggies. This is predominantly when a child can't independently walk, but we are currently campaigning to change the commissioning criteria so that children with a cognitive/behavioural/sensory disability who need mobility to keep them safe have access to this service. If an appropriate specification of equipment can't be provided then partial funding may be available through alternative schemes. The wheelchairs and buggies provided tend to be specifications that meet daily needs rather than those suitable for all terrains, and often won't come with weather protection or additional accessories, in which case again you may need to consider charitable funding or purchasing it yourself.

Organisations (in addition to Newlife) that may consider providing funds for a wheelchair, buggy and/or weather protection (for use with equipment provided by wheelchair services) include:

- [Boparan Charitable Trust](#)
- [Variety The Children's Charity](#)
- [Hospital Saturday Fund](#)

A standing frame should be provided to any child who has the ability to weight bear so that there are adequate options for a change of positioning and proactive health benefits associated such as improved bone density, respiratory function and digestion. Walking frames (if your child is assessed as able to use one) would normally be funded by the NHS and therefore you should discuss available options with your child's Physiotherapist or Occupational Therapist. If you don't have access to these professionals, then ask for a referral from your GP.

Will you need to use a beach buggy?

Most wheelchair beach buggy schemes are funded by the local authority so this should be the first place to call to find out if a particular beach has a scheme running that year. Availability differs from year to year, can depend on the time of year, or the wheelchair may be on rotation to another beach. Please call the council in the area you're visiting ahead of time for availability. Alternatively, you may want to find out if the tyres on the wheelchair/buggy used on flat terrain can be temporarily replaced if new tyres that are more suitable for the beach are purchased.



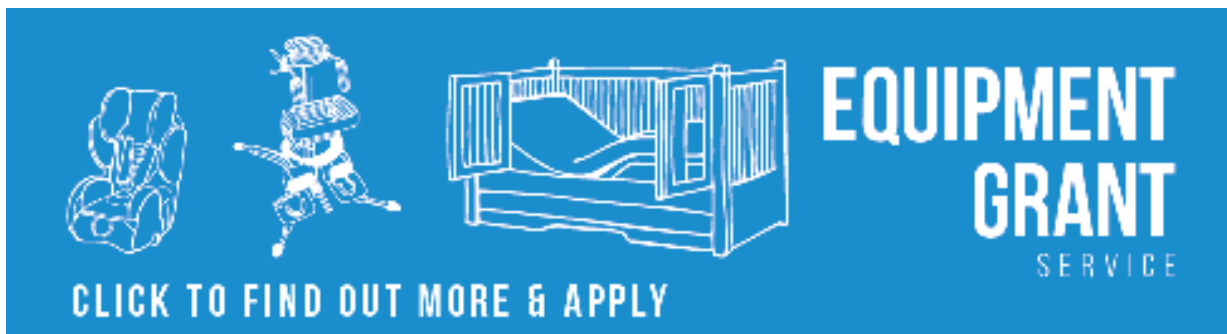
Do you need a communication aid or visual timetable?

You will know in advance of your adventure if your child is dependent on the use of a communication aid or visual timetable to help them through their daily routine and to communicate their wants/needs. If they do have appropriate equipment and resources for use at home, make sure to pack it so that your child is supported to adjust to a change of environment. Visual materials and use of symbols such as [Widgit](#) will often have associated [translation options](#) for use in other countries.

Will you need a specialist travel bed or a postural sleep system when staying overnight?

Children with cognitive, behavioural or sensory disabilities will often have an impaired sense of danger and therefore need an enclosed space within which they can sleep safely. Your local authority's Occupational Therapists or social workers may be in a position to assess whether alternative interventions or support strategies can be used to ensure your child's safety, but this can be hard enough in the family home yet alone in an unfamiliar environment. If a specialist bed is needed in the home, then funding should be available from your local authority, however this often means that their statutory responsibilities have been satisfied and a travel bed won't be funded too. If you plan to travel regularly as a family, then please ensure the equipment assessment identifies a bed specification that can be used daily but that is also transportable – there are some excellent options available.

The vast majority of sleep systems (which help ensure postural symmetry overnight) are easily transported. If your child doesn't have a sleep system, but has a postural management plan then you may want to discuss the benefits of the local health services funding one through your child's Physiotherapist.



Can you transport this equipment?

Don't simply consider how you transport this equipment, but also whether you need access to it during the journey as this will affect the order in which you pack the car or whether you need it available **during a flight**.

If you can't transport all the equipment then you may want to consider renting the equipment for the fixed period and arranging for it to be delivered to, and collected from, the place you are visiting. In this situation, you may need to ensure that additional arrangements can be made with your accommodation so that equipment can be signed in and out – and this may incur further cost if the equipment needs to stay after your check-out times.

Do you need additional insurance for the equipment you are taking?

You will need to liaise with your insurance provider to find out if your policy covers you to use equipment in multiple settings. Your policy will normally be determined by the extent to which you have ownership (which may not be the case if provided by local health or social care services) and the cost of the equipment, but can also be limited by the location you intend to visit. Holiday insurance booked when planning your trip may have a maximum coverage for any individual item you take with you so you may need additional insurance to cover the full replacement value if damaged, broken or stolen.

MEDICAL AND MEDICATION CONSIDERATIONS:

Do you need to get a repeat prescription to cover the period away from home? How should the medicines be transported and do you need to show proof of prescription?

Some medications may need to be kept chilled or be available to be taken at specified times during a journey so you will need to plan for the most appropriate way to transport your child's medications. Also, particularly when passing through customs, you may be asked to present a prescription so that they can allow them into another country. If in doubt about the best way to transport medications so that they remain viable for use, or the most appropriate way to prove the need for the **medication is genuine**, please seek guidance from your pharmacy or GP.

Does your child need medical equipment to monitor or maintain their health?

Some children will need their health observing closely no matter what kind of adventure you are venturing into, so remember to take a portable thermometer, blood pressure monitor, oxygen saturation monitor, blood glucose monitor, seizure monitor/alarm, video monitor – if clinically indicated as being important to your child. If in doubt, please speak to your GP.

“ Please be mindful of allergies and/or sensitivities when buying additional holiday items.

Do you have an up-to-date first aid kit that you can take with you?

Most children have some level of coordination issue depending on their age and their milestones, but children with cognitive, behavioural and/or sensory disabilities are more likely to incur injuries – particularly in unfamiliar settings. It is best to be prepared and carry a first aid kit that enables you to manage minor injuries

For more serious injuries, or in the likelihood that you may need health care during your adventure, make a note of the location and contact details for the closest Accident & Emergency department and walk-in centre to the place you are visiting so that you are aware of travel distances and available public transport routes.

Do you need to carry tolerable and effective pain relief with you?

Some children only tolerate certain types of medication delivered to them in particular/specific ways, so please consider this and carry effective pain relief for them that they will tolerate.

You may find it beneficial to have a list of conditions/additional needs prepared for your adventure – especially if their needs are very specific. This could be in the form of a hospital passport like the one developed by **SCOPE** which includes information on your child's likes and dislikes, how they communicate, and what care they need. Alternatively, take a personal care plan or copy of an EHCP/Statement of Educational Needs which should contain enough detail to help someone unfamiliar with your child's needs ensure all is well in the case that you are taken ill.

HINTS AND TIPS

There are lots of organisations that can arrange for you to hire an item of equipment for use on your adventure (fees may apply). Here are a list of a few:

- [Red Cross](#)
- [Tryb4uFly](#)
- [Wheel Freedom](#)
- [Wenman Healthcare](#)
- [Mobility Hire](#)

Disability grants are available – www.disability-grants.org & www.turn2us.org.uk are websites that can be searched for information on charities which may be able to assist with funding of both equipment and holidays.

Can you access additional support during a journey?

- The [UK Government](#) website has additional regional information about accessible taxis, facilities and fare concessions for public transport. It also has some good quality information about [UK transport services](#) that are available to help people with disabilities.
- [MENCAP](#) has information on subsidised travel in the UK for individuals with disabilities.
- For a useful guide to additional support services that should be available when flying abroad, visit the [UK Civil Aviation Authority](#) website but be sure to check in advance with individual airlines that appropriate arrangements can be made for your child.

Check for any COVID restrictions for the area you plan to visit, ideally these would be on government websites, as arrangements to keep your family safe can vary between localities and countries.

There are lots of resources available to help inform people you meet on an adventure of your child's additional needs, such as:

- [National Autistic Society](#) – "I am autistic" card
- [Autism West Midlands](#) - autism alert cards for people with autism
- [SHINE](#) - Shunt Alert card

Make sure to wear/pack appropriate clothes, such as a raincoat, sun hat, wellies, and umbrella so that you are prepared for all types of weather. Consider the benefit of taking a change of clothes too, in case something happens while travelling and make sure it is accessible during the journey.

DURING YOUR HOLIDAY

It is really important to think about the journey as part of the holiday. However, it can be difficult to avoid being swept up in the chaos and frustration. Try to focus on ways in which you can stay calm under increased pressure and recognise that stress is still stress even when achieving a positive change.

In addition, no matter how much planning and preparation you do for your trip it is highly likely that there will be unforeseen circumstances and having particular ways to create headspace for problem solving is really important. Perhaps consider whether any of these techniques could be used in the moment:



Breathe - deep breathing increases the supply of oxygen to your brain and stimulates the parasympathetic nervous system, which promotes a state of calmness. When you are starting to feel overwhelmed try this diaphragmatic breathing technique:

- a) *Sit or stand in a comfortable position.*
- b) *Relax your shoulders.*
- c) *Put a hand on your stomach and push your stomach out.*
- d) *Breathe in through your nose for 2-3 seconds. You should experience the air moving through your nostrils into your abdomen, making it expand. During this type of breathing, make sure your stomach is moving outward while your chest remains relatively still.*
- e) *Purse your lips (as if you're about to drink through a straw), press gently on your stomach, and breathe out through your mouth slowly for 3-4 seconds.*
- f) *Repeat these steps several times for best results.*

Loosen Up - perform a quick scan of your body to identify any muscles that are tight or tense. Clenched jaw? Raised shoulders? Gently touch or massage any of your body parts that are under tension to encourage total relaxation. It might help to imagine you're in a place that calms you, such as a beach, spa, or forest.

Stay present – it is easy to focus on what has not gone so well or worry about what might go wrong next, but it is really important to stay in the moment. Notice your surroundings, consider whether you feel safe and well, breathe, and focus on what you are doing at that specific moment. Take every part of your day step by step - often what we worry about doesn't end up happening anyway and if it does we will still cope – and remember we have survived 100% of our bad days up to this point!

Try this mindfulness technique to help you to stay present and focus on your environment instead of ruminating about your thoughts and concerns/fears:

- *Identify 5 things that you can see;*
- *Identify 4 things you can feel;*
- *Identify 3 things that you can hear;*
- *Identify 2 things you can smell;*
- *Identify 1 thing you can taste.*

In addition to managing your own emotional needs, there are practical ways to avoid additional stresses by meeting your child's needs. One way to do this would be to request the free loan of a **Newlife Play Therapy Pod** which provide a large quantity of specialist toys, of which most are small and mobile and therefore could be used during a journey. There are a huge variety of toys that are available for various ages and can offer suitable play options irrespective of the extent of the child's additional needs.

**PLAY
THERAPY
PODS**
FREE SERVICE
PODS AVAILABLE NOW!

82%

of parents had a better understanding of their child's needs.

77%

enjoyed quality time as a family through play with appropriate toys.

87%

of families report the specialist toys improved relationships.



While you may have ways of distracting your child for long periods of time, try to consider how beneficial these options are to contributing to the sense of adventure. For instance, instead of relying on using devices to watch their favourite films and listen to popular music, try to involve them in travel games that are adapted to their abilities. There are a variety of different options that may work during a journey, or on arrival, provided by **Change4Life** which can help elevate your experiences and build memories.

Not everyone will have a thorough knowledge of their child's sensory needs or ways to meet them, and additional support can be sought from **Sensory Integration Therapists**, but you may want to consider some of these general considerations that may avoid challenging behaviours stemming from senses being either under or overstimulated:

- Bring a 'sensory survival kit' with items that may help your child to stay regulated - for example, ear defenders to block out loud and unexpected noises, fidget toys, oral chew toys, a hooded top, cap or sunglasses for light sensitivity, weighted items (such as a blanket), etc.
- Children with sensory issues can often struggle with the motion and movement of a vehicle, so try to take regular breaks and encourage your child to look out of a window and into the distance - sitting facing forwards can also help.
- Use a visual timetable or 'Now and Next' cards to help with transitions and helping your child to know what is coming next during the day.
- Call ahead. Many airlines and some motorway services can accommodate families who require additional support and this may include providing a quiet or sensory play area.
- Additional services may also be possible such as providing a check in/departure experience where you do not need to queue, or pre-allocated seating to ensure that you are sat together during a flight.
- Make sure that you have your child's favourite snacks and drink bottle for the journey, as this can help to prevent a meltdown due to being hungry or thirsty.
- Dress your child in comfortable clothes and shoes that they can tolerate - this helps with any tactile processing issues.
- Activities can be calming and regulating for your child but may be hard to fit in when there is lots of sitting down during the journey. When the opportunities arise, try activities such as climbing stairs, pulling or carrying luggage or a backpack, doing wall or chair push-ups. Whilst sitting, you may want to suggest that your child tries to push on the sides of the chair and lift themselves up, push their hands together as hard as possible, or try giving themselves a tight hug – all of which can help aid regulation of senses.

HINTS AND TIPS:

- Remember to pack your camera (and batteries/charger) so that you can take precious photos while building memories. If you can, why not provide your child with the ability to take their own photos. If not, perhaps you could buy a scrapbook in which they can draw and stick items you collect from the adventure.
- Although a close proximity to child play areas and entertainment facilities may sound ideal, consider that staying at a distance from them may help with being able to have down-time during the adventure. A short walk to get to nearby playgrounds will mean that there are less unexpected sounds that trigger sensory reactions while trying to encourage your child to self-regulate their sensory needs.
- Help your child to look out the window for locations that mark particular points during the pre-planned journey. You may want to use visual aids to create a scavenger hunt that helps them understand how far into the journey they are.
- As some children may feel travel sick, you may want to help them self-regulate this by showing them particular pressure points that can be used to ease the nausea. If this is too difficult to achieve, then ensure you have medication that your child can tolerate that is safe for use alongside any other medications that will not trigger any allergies and/or sensitivities.
- Be kind and gentle with yourself and your child when the unexpected happens. Remember to breathe and try to stay calm. Try not to focus on judgmental looks that passers-by may give you and remain focussed on the fact that lots of parents have at some point been in a similar position and will understand that you are doing your best under challenging circumstances.
- Try to keep the unexpected situations, and things you find stressful, in perspective. Take a deep breath and ask yourself 'will this matter to me next week/month/year?' If the answer is no, don't give it more than five minutes of your time.
- Remember to find joy and laughter in all situations. You can laugh at funny situations you witness and equally you can laugh away the absurdity of circumstances happening to you. You can choose to laugh and smile whenever you want!

“ MOST IMPORTANTLY, FIND FUN WITHIN THE EXPERIENCE OF HAVING AN ADVENTURE WITH YOUR CHILD – TIME IS PRECIOUS. ENJOY YOURSELF - YOU HAVE EARNED IT BY ALL THE PLANNING AND PREPARATION YOU HAVE PUT INTO IT.

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ENJOY YOUR HOLIDAY