

# Keeping Well to Care Effectively

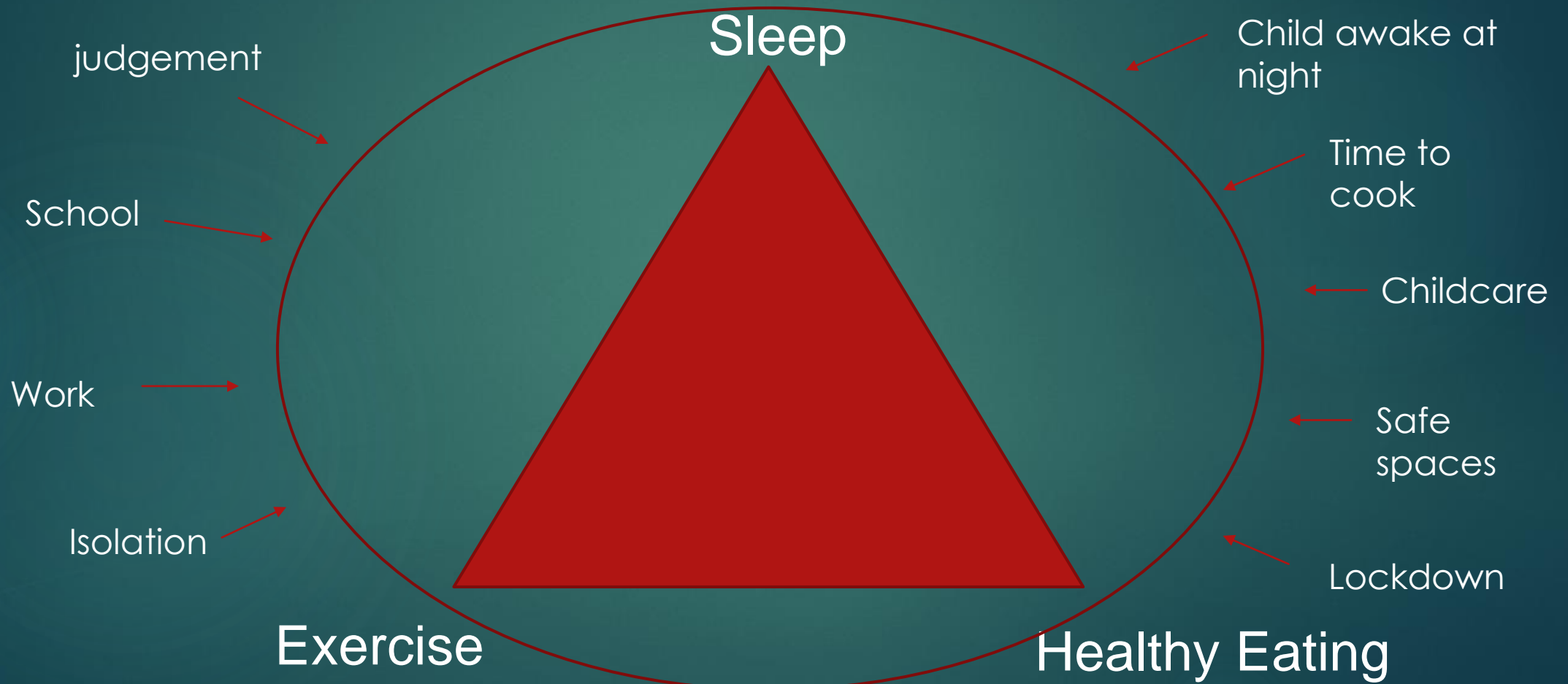
VICTORIA WICKS – PARENT/CARER

# My aims:

- ▶ To have a happy home
- ▶ To have a healthy home
- ▶ To ensure Olivia is given the opportunity to be the best that she can be

# My balance of needs:

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# Maintaining the balance-

## What impacts on the triangle

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- Perspective and acceptance
- My must do's – everything else is negotiable
- Time for me
- Dealing with the system

# Perspective and acceptance

- For a year I thought I was ok with Olivia's diagnosis, but I wasn't!
- I went to a SEND conference and I heard an autistic person talk about their life and their experiences.
- I realised that I was spending more time worrying about how Olivia was going to be, than understanding how she is/was.
- My stress levels dropped when I stopped stressing about the things that concerned me, and concentrated on the things that Olivia needed.
- Now I can honestly say that 'Olivia is autistic and it's ok!'

# Olivia's needs:

Understanding her needs takes significant stress out of the day.

- Sensory - Seeks light, Hypersensitive hearing, no sense of smell, seeks strong flavours, needs to feel her environment, needs to move constantly, under sensitive to pain
- Simple language
- Routine
- To know what is happening next

# Responding to her need to decrease stress

- The countdown from five
- Brushing hair routine
- Getting out of the bath routine

By responding to her need, there is less stress and more happiness in the home.

# Olivia must:

- Hold my hand when on the street
- Wear her seat belt when in the car
- Wear clothes when we have visitors, or when we are outside (this includes in the garden at home)
- Not do anything to hurt herself
- Not do anything to hurt someone else

Everything else either doesn't matter,  
or is negotiable!



# The supermarket meltdown

## ▶ In the supermarket child:

- Screams
- Drops to the floor
- Refuses to move

## People around are:

- Staring
- Tutting
- Judging

# Time for me - The triangle essentials

- Need to exercise
  - Exercise classes and the gym
  - Running
  - Dancing
- Need to eat healthily
  - Bulk cooking
- Need to sleep
  - De-Stress
  - Health – make sure I take medication
  - Child's ability to sleep

# Time for me – strengthening the balance

- Need hobbies
  - Knitting
  - Gardening
  - Baking
- Need to talk to other adults
  - Non-judgemental
  - Support groups

# Getting a diagnosis

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- ▶ I knew early that Olivia was different
  - ▶ Meeting physical milestones
  - ▶ She'll catch up
- ▶ Support from a childminder
  - ▶ Quarterly assessments that tracked her development over nine months
- ▶ Finally a referral
  - ▶ Due to the information I had pulled together the Health visitor referred us when Olivia was 18 months
- ▶ The move
  - ▶ We moved just before Olivia's 2<sup>nd</sup> birthday
  - ▶ I had conversations with SLTs who agreed to put her on the waiting list where she would have been had we not moved.
- ▶ The diagnosis
  - ▶ She was diagnosed at 37 months – This was hard, despite having battled through the system to get to that point.

# Preparing for Meetings/Conversations

- Speak to the teacher at an arranged time – ask for information
- Ask for an agenda.
- What do you want to know? Ask questions.
- Take notes
- Follow up with an email or notes

# Keeping well to care effectively

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- ▶ All of the things I have talked about impact on my wellbeing .
- ▶ All of the things I have talked about affect how good I am at caring.
- ▶ When I don't do the things I need to do, I fall apart....
- ▶ but I pick myself up again.
- ▶ I go back to my triangle, I get the balance, I get well...and keep caring!

# Resources

- ▶ Barnet Carers Centre - Provides support to carers of all ages. They also offer support to siblings of children with special needs.
- ▶ Parent network - <https://www.familiesinfofocus.co.uk/parent-network/>
- ▶ Parent network provides support to parents of children with SEND (with or without diagnosis). They run topical groups during term time, to support parents. Topics include Sensory needs, making your child's voice heard in EHCPs, tips for happy eating.
- ▶ Creative Education - <https://www.creativeeducation.co.uk/>
- ▶ They provide in-line training (can be done at any time) and are aimed at schools and parents. Many courses and webinars are free, you can sign up to receive email notifications of the free resources in any one week.
- ▶ Chicken shed theatre - <https://www.chickenshed.org.uk/>. Inclusive events. This has included on line during COVID-19 pandemic.
- ▶ Thames Valley Adventure Playground - <https://www.tvap.co.uk/>  
Adventure playground for children with SEND and their families.