Spinal Muscular Atrophy
AUSTRALIA INC.

SPINAL MUSCULAR ATROPHY:

THE HANDY INFO BOOK FOR THE CLASSROOM

Introduction

Welcome to the new school year!

Each year in the classroom there is always a variety of students from wonderful, diverse backgrounds. This year a student with Spinal Muscular Atrophy (SMA) is joining your class. We realise that not a lot of people know what SMA is or how to best support a child with the condition. Additionally, every child's journey and experience with SMA looks very different.

That being the case, this information booklet is designed to help make this an exciting transition for your student into the school system as easy as possible. Please use this guide to help you get to know more about both SMA and your new student. We hope that the practical information provided will support you to help students with SMA succeed at school.

If you have any questions, please don't hesitate to contact the student's parents/guardians. More information about SMA can be found at our website, www.smaaustralia.org.au

All the best,

SMA Australia

What is SMA?

Spinal Muscular Atrophy (SMA) is a rare genetic condition which affects 1 in every 8,000-10,000 children in Australia. As SMA is genetic, it cannot be caught like a cold or flu. It's instead caused by a change in our DNA that can be inherited from our parents, even if they don't have SMA themselves.

SMA affects the lifespan of motor neurons, which are the cells that pass messages from the brain to the muscles that help you move. In people with SMA, these neurons are lost much quicker than in those without SMA. This means the muscles become gradually weaker, and over time this can affect lots of different bodily functions. Some effects are visible: these include fatigue and trouble walking, talking, and writing. However, muscle weakness can also make it more difficult to breathe and fight off infections and illnesses. Sometimes, just existing with SMA can be tiring.

Every person with SMA has a different experience. This is due, in part, to the many different symptoms people with SMA can have. This range is because there are four main types of SMA (Types 1-4), which are classified by the age that symptoms started to occur.

Some common features you might see between these types in children with SMA are:

- ★ The need to use mobility aids such as a scooter or wheelchair.
- ★ Trouble sitting upright by themselves.
- ★ The need for help with standing up and/or walking.
- ★ A decline in strength as they get older.
- ★ Trouble moving their heads by themselves.
- ★ Trouble climbing stairs by themselves.
- ★ Needing to type instead of write.

It is important to remember that while this condition can affect lots of different bodily movements, it does not affect a child's mental ability. SMA also does not define those who have it. People with SMA often live exciting, full lives, and we're sure you'll see the bright and diverse nature of this with your new student.

Please take the time to read the next page to learn about

______________________________ and how you can best support them.

(Child's Name)

About the Child

Photo
of Child

Meet ______________________________
(Child's Name/Surname)

____________________ is _______ years old.
(Child's First Name) *(Age)*

____________________ has SMA.
(Child's First Name)

For ____________________, this means:
(Child's First Name)

Please use this space to talk about accommodations your child might need, such as help opening textas, extra time off of class for doctor's appointments, or if they require a mobility aid.

Kids with SMA can get tired a little quicker than other kids.

When ________________________ is tired, they will:
(Child's First Name)

Please use this space to describe signs that you child may be tired. We know fatigue can be built up over days and can take many different forms. Helping your child's teacher recognise early signs can help to get your child the best support they need that day.

About the Child

Whilst SMA affects how ______________________________ uses their body,
(Child's First Name)

it does not affect their brain. ______________________________ loves to:
(Child's First Name)

Tell us about your child. Perhaps if they're looking forward to school, their hobbies, cheeky personalities or even their favourite animal and birthday!

Contact Information

If you have any more questions about how to help ______________________
(Child's First Name)

adjust to school, please feel free to contact their parent/guardian on:

PERSON 1

Name/Surname: ______________________

Relationship to Child: ______________________

Email Address: ______________________

Mobile Ph: ______________________ Work Ph: ______________________

PERSON 2

Name/Surname: ______________________

Relationship to Child: ______________________

Email Address: ______________________

Mobile Ph: ______________________ Work Ph: ______________________

Changes to improve the school experience for children with SMA

One of the most important things to remember about kids with SMA is that their mental abilities are not affected, and they're just as smart as any of their other classmates. If they talk more slowly or differently to the other students, it is only because their speaking muscles may not work very quickly.

Keeping that in mind, one key tip from the SMA community is to not talk about them without them. People with SMA can often advocate for themselves. If you want to discuss the child or an issue in the class, please talk to them or their parent/guardian first, before speaking with the whole class.

In order to make this transition easier, and for the student to have as normal a school experience as possible, several accommodations may be put in place. Some that you may see within the classroom and around the school are:

- Ramp installation.
- Lifts.
- Time taken out to attend medical appointments.
- Modified PE curriculums.
- Class seating plans.
- Classrooms be close together to reduce distance travelled.
- Automatic doors.
- Toileting rails.
- A quiet place to go if the student is fatigued.

Talking to other students about SMA

Talking to your class about SMA can be tricky; we understand it can feel difficult to balance educating about a condition without making it come across as a defining characteristic of the person.

We encourage open and engaging conversations about SMA in the classroom. As a teacher, you could frame these in many different ways:

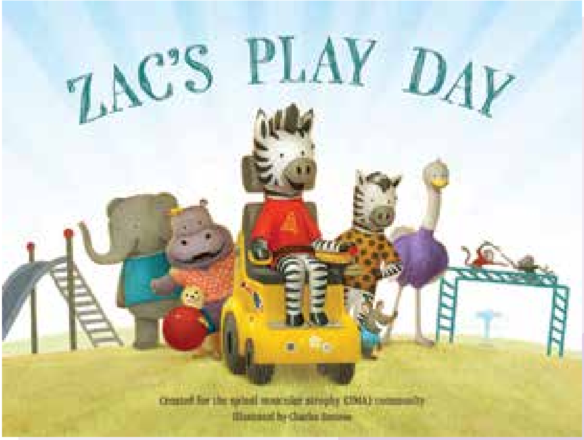
- ★ Highlighting that whilst they have SMA, your student is still a kid. A child with SMA wants to make friends, talk, laugh, and play with other students as much as any other.
- ★ In the context of tolerance. Reminding students that everyone needs help with different things: for example, some children have help with their reading, some with writing, some with their ability to focus etc.
- ★ In the context of inclusion. Letting students know that, whilst a child with SMA wants to play with their friends, they may not be able to run around or play high-energy games like other kids. Other children can be encouraged to ask those with SMA how they would like to play, and to make up new games which the child with SMA can take part in.

It is also very important for other students to know that mobility aids like walkers, scooters, or wheelchairs are just like their bodies. While it might be excitingly different, like with our own bodies, we shouldn't touch or climb on them without permission! Letting students know to not sit or stand directly behind a wheelchair is also a good tip to make sure no accidental collisions occur.

To introduce some of these ideas to the classroom, a picture book developed by SMA Australia called "Zac's play day" has been made. This book is free, and you can get e-copy for the classroom from this link:

https://www.togetherinsma.com/en_us/home/resources/zacs-play-day-e-book.html

We recommend this as a fun, engaging and inclusive way to begin learning about SMA in the classroom!



Thank You

Thank you for taking the time to read this information about SMA.

To learn more about SMA and its genetics, you can visit our website, **www.smaaustralia.org.au** or download the “SMA Community” app from the Apple Store or Google Play.

If you have any further questions about your particular student, please don’t hesitate to contact their parent/guardian. Questions are always welcome as clearer communication can only help make this transition easier!

Credits

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