



School Advocacy Guide

Responding to needs of young people
when a parent has dementia or brain injury.

School Advocacy Guide: Responding to the needs of young people when a parent has brain injury or dementia.

This guide was written by Associate Professor Jeneva Ohan. The artwork and design was created by Jean Low.

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The **Keep Us In Mind: Responding to the Needs of Young People when a parent has Dementia or Brain Injury Project** was generated by Dr. Angelita Martini from the Brightwater Research Centre, and developed in collaboration with Jeneva Ohan from the University of Western Australia. This project was supported by Lotterywest.

For further information about this research and to find information and resources for families and young people when a parent has dementia or brain injury, please contact us at <https://brightwatergroup.com/research/>

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**School is so important.
Children spend a lot of their
awake life at school.**

**When a parent has had
an injury or illness, school
provides children with a
needed sense of belonging to
their community, normalcy,
routine, and structure. In
addition, education itself is
provided at school.**



But your child might find it hard to be as successful at school as they used to. This might be because...

- They don't have the same level of parental support in learning (e.g., practicing reading, times tables)
- They are distracted by worrying about the parent and not attending to their lessons
- They feel disengaged from their friends as now their challenges are shifting, and they feel 'different', or don't feel supported.
- They might get teased because of the parent's changes

Each child, family, and school is different.

You are this child's best advocate

Working with your child's school is crucial. Without discussion, the school will not know how children are affected, what to look out for, and/or develop a plan to help.

By talking with your child's school, you are not only helping, you are also being their advocate, and modelling for your child how to advocate for themselves.

Discussing the injury or diagnosis with your child's/ children's school

Parents often think about how to talk with their child's school about their own or a co-parent's brain injury or neurological diagnosis. This is a personal decision, and what works for your family and is in the best interests of your child might differ from what works for another family. Here we offer some ideas to think about and guidance that might be helpful in making this personal decision.

Who should I speak to?

You might think about:

Who spends the most time with my child?

Your child's teacher is most likely to be the person spending the most time with your child, and therefore would benefit from knowing about what could be affecting your child's behaviour and learning at school.

Who do I feel comfortable talking with?

There might be a central person, like a Deputy Headmaster, school nurse, or counsellor, with whom you feel comfortable speaking. This person could serve as your contact person.

You could talk with more than one person,

depending on how your child's school is organised and what is in your child's best interests. For example, you could request a joint meeting with a teacher and school counsellor.

What should I say?

Knowing what information your child's school needs to best support your child at school can be challenging to answer.

Some information you might like to consider discussing:

The parent's **diagnosis, and what that means for your child at school**. For example...

- You might have less time or ability to help your child with homework, even though you really value education.
- You might now need a stick to walk and your speech is slurred and you know your son/daughter is worried about being teased when you come to school.

Strategies you think could help keep your child on track with work outside the classroom, for example:

- The possibility of a homework club.
- For you and the teacher to have a school-home communication book in which the teacher records homework that can be easily checked.

If you can't think of any strategies, maybe others at the school can.

What you are hoping for your child at school. For example:

- hope that your child learns that school and home are working as a team.
- hope that your child experiences understanding, and that school is a safe place.

Express that you are **open to changing strategies**, and realise that new issues might arise. Let the teacher know how to get in contact with you, and ask how it is best to contact them.

On page 7, you'll find a sheet with these ideas started that you might find helpful to fill out.

I know what I want to say... How might I go about saying this?



Scheduling a time to meet with the teacher often works better than trying to 'catch' them.



You can choose what information you think will be most helpful for your child's teacher to know in order to help understand your child and their needs.



You might find it helpful to plan what you would like to say before you talk with your child's teacher (or send an email). If you meet in person, having a few notes as to what you feel is most important for them to know will help make sure that you get this information across.

If you find it difficult to talk about this, you could bring someone with you (e.g., another family member)



There are different ways to communicate. If you can't or would rather not meet with someone at your child's school, you could try sending an email instead.



Do not worry if you forget to say something, or if a new issue comes up. This is about starting a relationship and opening communicating with your child's teacher, not a one-time meeting.





Should I mention this to my child?

Being honest with children is important in building a solid relationship. Depending on their age, they might not be involved in the discussion or the decision making.

Letting the child know who you have spoken to about what, and why (e.g., what you are hoping to achieve for your child) not only builds honest communication, but also shows the child that you are their advocate.

Developmental Considerations

Although this resource has been designed for primary school-aged children, it can also be useful for other age ranges...

Infants, toddlers, and pre-schoolers: you don't yet have school to discuss these issues with, but you might still wish to talk with any other childcare providers. In this case, you might find some of this still helpful in guiding what you want to say.

Older children and adolescents: Older children and adolescents might not want to discuss these issues with you or their school, but would still benefit from this discussion. Think about teaching them to be advocates for their own needs, and modelling for them how to do this by involving them in some of these decisions and discussions. You could both try advocating together, or one at a time. For example, you might sit down with an adolescent and problem-solve who to talk to, and what is important to say. We have included a separate resource for parents who wish to involve their children in these decisions and/or discussions.

Primary School:

What I'd like to tell my child's school

You fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections... different families will have different needs. If you have more than one child, you might also like to make a different sheet for each.

01

The **brain injury or neurological diagnosis and what that means for my child at school.** You might include a) how the injury/illness impacts on the parent, and b) how the injury/illness affects your child at school.

02

Strategies that you have found helpful, or might find helpful. You might have some ideas as to what would work for you and your child (such as introducing the school counsellor and opening the door to communication; a homework club; emailed reminders for forms), or you might not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher knows.

03

What you are hoping for your child at school. What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for your child at school?

04

Express that strategies might need to change, and new issues might arise. Advise the teacher **how to get in contact with you, and ask how it is best to contact them.**

Middle & High School:

What we'd like to tell the school

You can fill this in if you think it would be useful for you to organise your thoughts. You can add, change, or delete any sections... different families will have different needs. Many heads are better than one – so try involving both caregivers and children/adolescents in completing this.

01

The **brain injury or neurological illness and what that means for me at school.** You might include a) how the injury or illness impacts on the parent, and b) how the injury or illness affects you at school.

02

Strategies that you have found helpful, or might find helpful. Depending on how the parent's brain injury/illness impacts on you at school, you might have some ideas as to what would work to support you (e.g., speaking with a school counsellor, access to a homework club). If you do not have any, in which case you could suggest trying to brainstorm ideas. If you are open to new ideas, then you might add this so that the teacher/school knows.

03

What you are hoping for at school. What are you hoping to achieve in sharing this with the school? Are there any particular goals or hopes that you have for this school year or term?

04

Express that strategies might need to change, and new issues might arise. Offer the teacher **your best contact details, and ask how it is best to contact them.**

This material is based on.

Ohan, J. L., Eaton, K., & Corrigan, P. W. (2016). *Starting the Conversation: Do you want to talk about your child?* [Unpublished therapy manual, based on the Honest, Open, Proud Program]. School of Psychological Sciences, University of Western Australia.

Date: _____

Homework

Any notes (positive or negative) about:

- Listening
- Participating
- Following directions
- Academics
- Language
- Play time

Notes about anything checked off:

Parent's initials: _____

Notes from Parents (if any):



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