

Bridget Kelly

Printing Shapes, 2024

A story about Joe getting good palliative care



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How to use the story



This story is about **palliative care**.

Palliative care is help for people who have a serious health condition that they will die from.



You can ask for help to read this story.

You could ask

- A person in your family
- Your support worker
- A friend.



You can talk to someone you trust about your feelings.



You do not need to read all of the story at the same time.

Not bold

Bold

There are some words in **bold** in this story.

Bold means the letters are thicker and darker.



We explain what these words in **bold** mean.

Who made the story



3DN wrote this story.

3DN is short for the Department of Developmental Disability Neuropsychiatry.



When you see the word ‘we’ it means **3DN**.



3DN is a **research group** at the University of New South Wales Sydney.



A **research group** is people working together to learn more about a topic.

What is shared in this story



We share **Easy Read** information sheets in this story. **Easy Read** uses simple words with pictures.



When you see an **Easy Read** picture it means there is an information sheet.



When you go to the *website link* it will take you to another place on the internet.

About the story



This story is made up and not about a real person.

It might not happen to you.



This story is about Joe.
Joe has a serious health condition.



This story is about Joe getting **palliative care**.



Palliative care is help for people who have a serious health condition that they will die from.



When a person dies it means their body has stopped working and their life has ended.



Palliative care helps people manage their **symptoms** so they feel well until they die.



Symptoms are problems people might have with a health condition.

It might be things like having pain or feeling sick.



Palliative care is managed by **health workers**.

Health workers might include doctors and nurses.

Why we made the story



People with intellectual disability often find it hard to get good **palliative care.**



We want people with intellectual disability to have good **palliative care.**

The people in the story



This story is about Joe.



Joe's **supporters** are his

- Sister
- Disability support worker



Joe has a family doctor



This story has other **health workers** in it.

A story about Joe getting good palliative care

About Joe



Joe lives in an apartment by himself.



Joe likes to walk his dog and spend time in the community garden.



Joe gets support from his sister and his disability support worker.

Stop Hello Eat
Words
person Day Open



Joe likes to communicate by

- Talking with simple words
- Using **Easy read**
- Using pictures.

Joe goes to his family doctor for help



Joe has a serious health condition that he will die from.



Joe has been

- Feeling sick
- Having more pain.



Joe made a time to see his family doctor.



Joe and his disability worker met with his family doctor to get help.



Joe and his doctor talked about getting help from a **palliative care team**.



A **palliative care team** are **health workers**.



The **palliative care** team will help Joe feel well and have less pain.



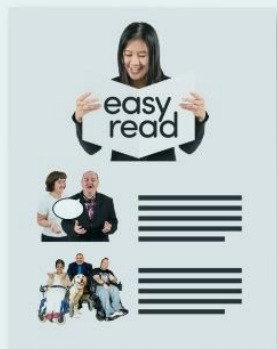
The family doctor tells the **palliative care team** about Joe.

Information about palliative care



Joe's family doctor gives him an **Easy Read** information sheet about **preparing** for **palliative care**.

Preparing means to get ready for something.



To find the information sheet about **palliative care** go to - 3dn.unsw.edu.au/improving-palliative-care-resources#preparing

The information sheet is about



- What **palliative care** is



- Who might be involved



- Questions that **health workers** might ask.



The information sheet about **palliative care** also has parts to fill out.



Joe looks at the information sheets with his **supporters**.



The information helps Joe to understand what **palliative care** is.



The information helps Joe to think about questions he might like to ask his **health workers**.



Joe feels less worried about seeing the **palliative care team** after reading the information.



The information sheet helps Joe think about who he wants to be involved in his care.



Joe decides that he wants his sister and disability support worker to be involved in his care.

Joe's first palliative care appointment

Preparing for the appointment



The **palliative care team** reads important information about Joe from his family doctor.



The **palliative care team** call Joe before the appointment to ask if he needs any **reasonable adjustments**.



Reasonable adjustments means changing the way things are done to make it fair.



Joe tells the **palliative care team** how he likes to communicate.



Joe said he wanted to bring his sister and disability support worker to appointments.

During the appointment

Stop
Hello Eat
Words
Person Day Open



The **palliative care team** use simple words and **Easy Read** to communicate with Joe.



The **palliative care team** ask Joe



- What do you like?
- What don't you like?
- What is important to you?



Joe said that he wants the **palliative care team** to visit him at home.



The **palliative care team** include Joe in decisions about his care.



The **palliative care team** give information to

- Joe's sister
- Joe's disability support worker.





Everyone talks about how they could work together to take care of Joe.

Information sheet for everyone to work together



Joe uses an information sheet to help everyone work together.



To find the information sheet about working together go to - 3dn.unsw.edu.au/resources/improving-palliative-care-resources#myteam



The sheet asks questions like

- Who should be involved in **palliative care**?
- How should **supporters** be told important information?

Making a care plan



The **palliative care team** talk to Joe and his supporters to write a **care plan**.



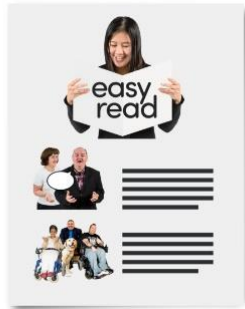
A **care plan** says what needs to be done for a health condition.



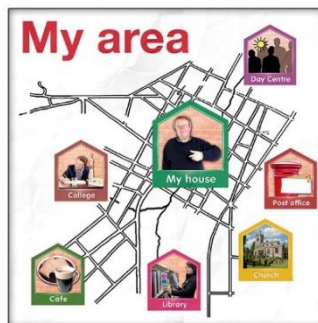
The **palliative care team** make sure everybody

- Understands the plan
- Is happy with the plan.

Information about palliative care services



The **palliative care team** give Joe **Easy Read** information about **palliative care** services.



The sheet has information about **palliative care** services in Joe's local area.



To find the Palliative care services sheet go to - 3dn.unsw.edu.au/improving-palliative-care-resources#services



The sheet must be given to a **palliative care team** to complete.



Information about support for the future makes Joe feel less worried.



Everyone knows who to call if they need more help.

After the palliative care appointment



Everyone follows the plan to support Joe.



Joe is given **medicine** to help with his pain and sickness.

Medicine is sometimes called medication or drugs.



The **palliative care team** visit Joe in his house every week.



Each time Joe sees the **palliative care team** everyone talks about



- What Joe likes about his care



- If his needs have changed.



Working together helps the **palliative care team** to understand Joe's wishes and needs.



Joe's sister and disability support worker know how to support Joe.



Joe is happy that everyone is working together in a way he wants them to.

This is the end of the story.

Word list



This is a list of some words used in this story. It tells you what the words mean.



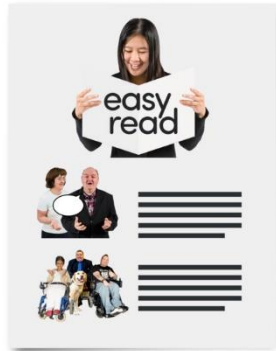
Care plan

A **care plan** says what needs to be done for a health condition.



Communicate

To **communicate** is how you understand and share your feelings or information.



Easy Read

Easy Read uses simple words with pictures.



Family doctor

Family doctor is

sometimes called a GP.

A GP is the doctor that you see when you are sick or need a health check.



Medicine

Medicine is sometimes called medication or drugs.



Medicine can be in

- A tablet
- A pill
- A drink
- An injection



Palliative care

Palliative care is help for people with a serious health condition that they will die from.



Reasonable adjustments

Reasonable adjustments

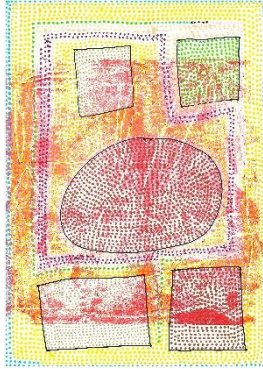
means changing the way things are done to make it fair.



Supporters

Supporters are people that help with care or daily life such as friends, family or carers.

Who made the art



The front and back
cover art was made by
Bridget Kelly.



The art in this story
was shared by Studio
ARTES

www.studioartes.org.au

Artwork by Bridget Kelly

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