

Bill of Rights for Teens with a Family Member Living with an Advanced Serious Illness

As teens with a family member living with an advanced serious illness, we have the right to:

- Be informed about the diagnosis, prognosis, progress of the illness, and treatment.
- Ask any questions about the illness, and have them answered honestly.
- Be given specific information about the illness in regards to symptoms we can expect.
- Choose to attend doctor's appointments (or not).
- Set boundaries for ourselves by taking breaks from hearing information about the illness when needed.
- Experience anger, sadness, numbness, etc. — at doctors, the medical system, the person with illness, other family members, and the illness itself.
- Be happy at times with or without feelings of guilt — and feel happy even when others aren't.
- Grieve in our own ways without societal pressures; no expectations, "shoulds, or "rules" of grief.
- Say no to caregiving sometimes and find ways to give care to ourselves.
- Decide what information we share about the illness with people outside the family.
- Decide when we feel ready to share about the illness with others.
- Have our own beliefs about life and death, even if they're different from our family, friends, and the person with illness.
- Ask for help, even when it's hard to — and even when someone in our family needs a lot of help right now, too.
- Grieve while our person with the illness is still alive.

This "Bill of Rights" was created by teen participants in Dougy Center's Pathways Program for when a family member is living with an advanced serious illness.

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