



# TEENAGE (IN)VISIBILITY

How to empower adolescent cancer patients  
in and out of hospital

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*Every child with cancer deserves the best care!*

# Conflicts of interest



- None applicable

# First things first

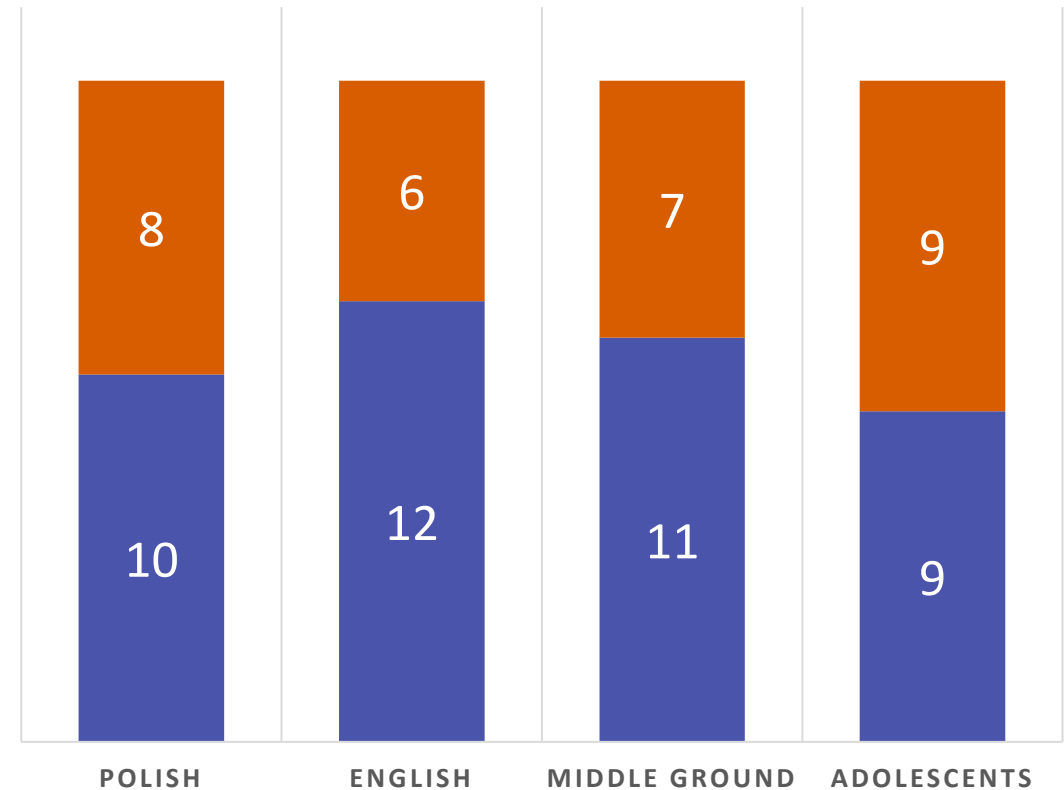
- Younger children (single-digit age, mostly) awaken more emotions
- Emotions = engagement
- Engagement = support
- Teenagers (and parents) have more reservations – such as self-image, peer pressure, rebellious stage of development

# About „teenagers“

- Language-based definitions:

- 11-18 years of age – Polish
- 13-18 years of age – English
- 12-18 years of age – middle ground
- adolescents – 10-18 years of age

■ Not being a teenager ■ Being a teenager



# Are there really *that* many?

- Between 2000 and 2020 in Poland:
  - 13.000 adolescents (ages 10-19) were diagnosed
  - On average, adolescents total about 53% of all diagnoses (ranging from 47% up to 59%)

Data after: Polish National Cancer Registry.  
Limitation of predefined age groups applies.

Year / Age group	00-04	05-09	10-14	15-19	TOTAL	% 10-19
2000	289	222	248	500	1259	59%
2001	296	252	261	508	1317	58%
2002	307	220	261	487	1275	59%
2003	295	227	255	474	1251	58%
2004	286	225	256	457	1224	58%
2005	333	219	248	489	1289	57%
2006	315	222	228	485	1250	57%
2007	302	197	226	459	1184	58%
2008	378	182	213	434	1207	54%
2009	365	203	233	430	1231	54%
2010	305	194	180	357	1036	52%
2011	336	176	174	380	1066	52%
2012	321	189	180	359	1049	51%
2013	334	208	186	347	1075	50%
2014	350	211	158	341	1060	47%
2015	319	212	168	352	1051	49%
2016	321	229	155	326	1031	47%
2017	331	200	191	359	1081	51%
2018	338	210	215	329	1092	50%
2019	350	224	220	348	1142	50%
2020	324	246	217	306	1093	48%
<b>TOTAL</b>	<b>6795</b>	<b>4468</b>	<b>4473</b>	<b>8527</b>	<b>24263</b>	

# Under our care – *Cape of Hope* clinic



- Just in the *Cape of Hope* clinic in Wrocław, Poland, between 2021 and 2023:
  - 299 new patients were admitted
  - ca. 30% of them were *teenagers*

<b>CAPE OF HOPE</b>		
2021-2023	Number	%
<b>TOTAL new cases</b>	<b>299</b>	<b>100%</b>
ages 11-18+	96	32%
ages 12-18+	84	28%
ages 13-18+	84	28%
ages 0-9	190	64%
ages 10-18+	109	36%

Data after: Data & Research Team, Saving Kids with Cancer Foundation

# Let's look at the (under)representation

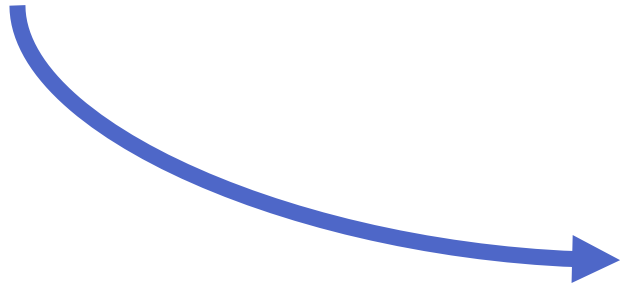


- UK-based foundation gifting unique items to children with cancer
  - **160** published stories of young recipients since 2013
  - Stories divided into three age groups: 0-5, 6-12 and 13-18
  - Of those 160, **140 (87,5%)** are of children aged 0-12
  - **Only 20 stories concern teenagers.**
- Poland-based paediatric oncology foundation
  - **219** published stories of children with cancer since 2016
  - Plus three stories of adults who are still battling cancer diagnosed earlier
  - Of those 219, **172 (79,5%)** are of children aged 0-10
  - **Only 47 stories concern teenagers.**

# The kicker?



## This is about us.



This is also our act of contrition and promise for the future.

- Poland-based paediatric oncology foundation
  - 219 published stories of children with cancer since 2016
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  - **Only 47 stories concern teenagers.**



# Teenagers are mostly shown as...

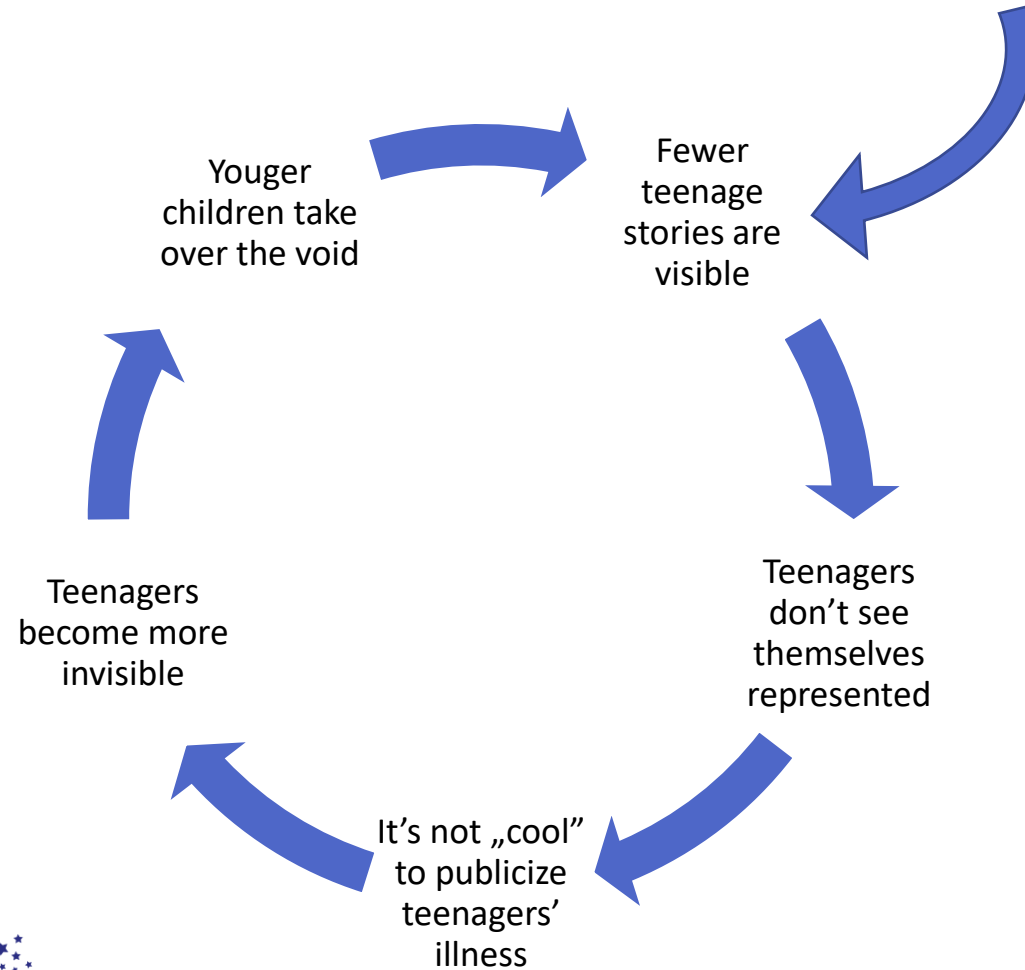


- Survivors of young-age cancer
- Adults – telling their past story

... and here comes the invisibility.

- In-clinic activities
- Proportions of material donations (e.g. LEGO sets)
- **Inability to self-determine, become individuals, become subjects**

# Vicious cycle – younger kids get publicity



# A few examples

## Helping young cancer patients ride their way back to physical fitness

**Example:** an organisation that provides bikes to children cancer patients to boost their activity levels.

Stories illustrating the message show a seven-, nine- and three-year-olds.



### Max

Seven-year-old Max has several disabilities as a result of a rare form of metastatic ependymoma. He received his specially adapted trike and trailer in 2021. Eighteen months later, Max is now pedalling and steering independently and is a member of a cycling club, attending with a friend from school.

His mum said: "Having this trike has brought normality to our lives. Max can bike like any other child can and our family can go out together for bike rides. The joy and memories the trike has brought us are truly priceless."

### Emma

Nine-year-old Emma was diagnosed with metastatic Ewing sarcoma in her right femur which is now severely damaged. She has reduced flexibility in her right knee and is no longer able to run, jump or do anything that would result in a strong impact on her legs.

Her mum said: "Our physiotherapist mentioned she could see her leg muscles are not wasting as quickly/strengthening and she even puts her feet down a bit flatter. What a difference the trike has made already to Emma!"



### Mollie

Mollie was diagnosed, aged three, with parameningeal rhabdomyosarcoma behind her left eye, causing her to lose sight in it. As she learnt to cycle, she lacked confidence, was very anxious and didn't enjoy it, saying her bike felt "wobbly". However, as soon as she got on her new bike, she became so much more confident, cycling two-and-a-half miles!

Her mum said: "The correct bike has really made a huge difference for Mollie, and it also reflects that cancer isn't over once chemo stops. Late effects impact kids' lives in many ways and CFC recognises this and helps children be children despite their diagnosis."

# A few examples

## How my cancer journey fuelled my strength and determination to succeed in sport



Jake holding his England international futsal shirt

*Jake Heasman was diagnosed with a brain tumour when he was two years old, leaving him visually impaired. He tells us how his experiences of cancer helped drive him on to sporting success.*

My name is Jake, and I'm 18 years old. I currently play for England's partially sighted senior futsal squad and can honestly say that I've been able to transfer some of the lessons that I've learnt

through treatment. Sport and treatment periods can both be like a rollercoaster, with some occasional positive news providing motivation to continue during the toughest moments.

### Trying my hand at futsal

My love of football continued throughout this tough period and a new opportunity came my way. Through the Blatchington Court Trust, a charity for the partially

**Example:** a survivor's story. Even though Jake is a teenager, he recounts his cancer journey from when he was two years old.



**Example:** Leah was diagnosed aged thirteen. However, she is now in her early twenties and recalls a story from 8-9 years prior to having written the story in 2022.

### Real Stories: Life changing diagnosis

"I know how precious life is, it isn't the life I wanted or the life I thought I was going to have, but it's still a life". Leah was an active, energetic and sporty 13-year-old who was diagnosed with stage 1 spinal ependymoma. Leah opens up about what life is like after a cancer diagnosis, the impact her diagnosis has had on her daily life, her mobility and the chronic pain she experiences. [Watch the full video here](#)



# A few examples



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**Example:** one of our own biggest campaigns each year, encouraging people to assign 1,5% of their yearly income tax to our Foundation. Pictures are from the 2024 campaign.

# Additional challenges

- Overprotective/helicopter parents, babying leading to developmental regression
- (Self)isolation from peers
- Lack of self-assurance, negative self-image, body negativity, especially during puberty, and sexual education
- Feelings of resignation, depression
- Inability to go through rebellion, first experiences, mistakes, emancipation
- Acute self-awareness - ability to read and „doomscroll“

# What can we do?

- Psychological support – for both patients and parents
- Encourage individuality and independence – individual developmental therapy
- Tools for restoring self-worth, dealing with negative emotions, overcoming the mundane
- TEACH:
  - About what the treatment means for the body
  - About ways to talk to friends
  - About expressing oneself
  - How to use social media and the internet responsibly
- Talk TO them, not AT them or just ABOUT them

# But how can we remedy this?

- Don't tell teenagers what to do. Ask them what **they** want to do.
- Provide adequate psychological support.
- Let them know they can express themselves.
- Let them ask embarrassing questions.
  
- Show them that they are still... **the same.**



# Here's what **they** wanted:



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# Our Big Idea for 2024/2025



- Goal 1: Show that teenagers with cancer **EXIST** within the society
- Goal 2: Empower them to take up space, be themselves, express their individuality
- Haute couture fashion shoot with **Zuza Krajewska**, award-winning photographer
- Big reveal – as much exposure as possible, opening in a gallery, with outdoor element
- Limited edition publication – fashion album with behind-the-scenes shots

# Further ideas

- One-on-one sessions – coaching, skills training, mentorship
  - A movie club/book club – as long, as **they** choose when, what and why
  - Sports/e-games watching
  - Study materials for each teenager individually, tailored to their interests
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- Good practice example: St. Jude Children’s Research Hospital „Teens&20s” section on the *Together* website.



**Cancer may affect your life, but it doesn't have to *DEFINE* you**

# Acknowledgements



- Materials used came from:
  - Contact Magazine, issues 98 and 99, spring and summer 2023
  - Saving Kids with Cancer's own campaigns
  - Children with Cancer UK's March 2024 newsletter
  - <https://together.stjude.org/en-us/teensand20s.html>
- Data came from:
  - Polish National Cancer Registry
  - Saving Kids with Cancer's Data & Research Team
  - Own analysis



**saving kids**  
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**CCI  
EUROPE  
2024**

15-18 May 2024  
Milan, Italy

# Thank you!

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