



CRITICAL AND OFTEN MISSED STEPS IN LAUNCHING ADVANCE CARE PLANNING FOR YOUTH: PARENTAL PERSPECTIVES

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on Pediatric Palliative Care
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FN MOTOL



2. LÉKAŘSKÁ
FAKULTA
UNIVERZITA
KARLOVA



Nadace
rodiny
Vlčkových



How to help AYA's to be heard





AYA population
15-29 yrs 18.5 % (2 mil.)

deaths annually
53 deaths (15-19 yrs)
249 deaths (20-29 yrs)

www.nzip.cz/modul/datove-zpravodajstvi

approx. 13k children in need of PPC



my background
pediatric oncology
palliative medicine

University Hospital MOTOL



Pediatric Supportive Care Team
150 new referrals per year

How to help AYA's to be heard



How to help AYA's to be heard in a culturally appropriate way





Choose What Provides You the Most Comfort, Say What Makes You Feel Supported, Write What Decisions Bring You Peace, Voice Your Thoughts and Needs

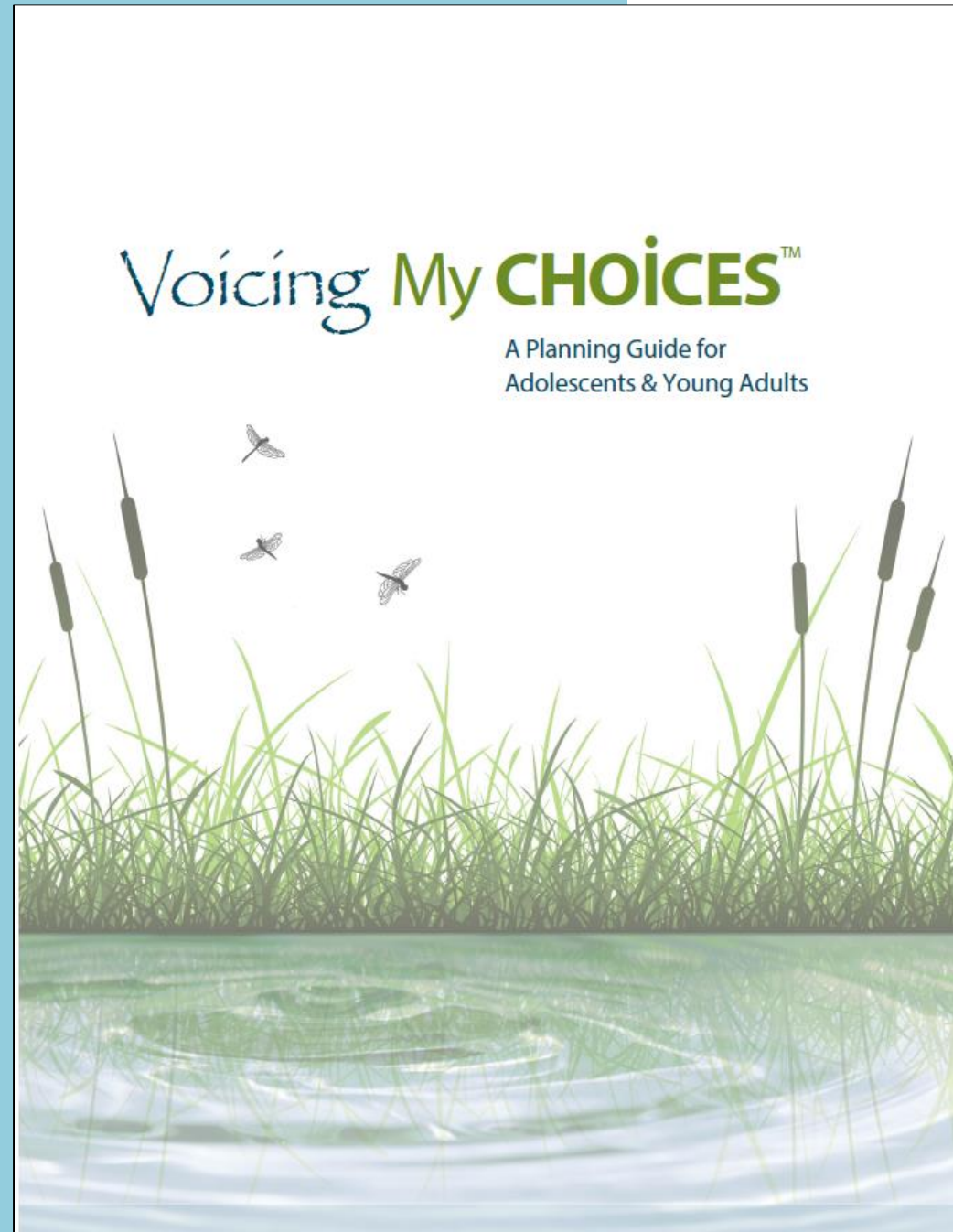
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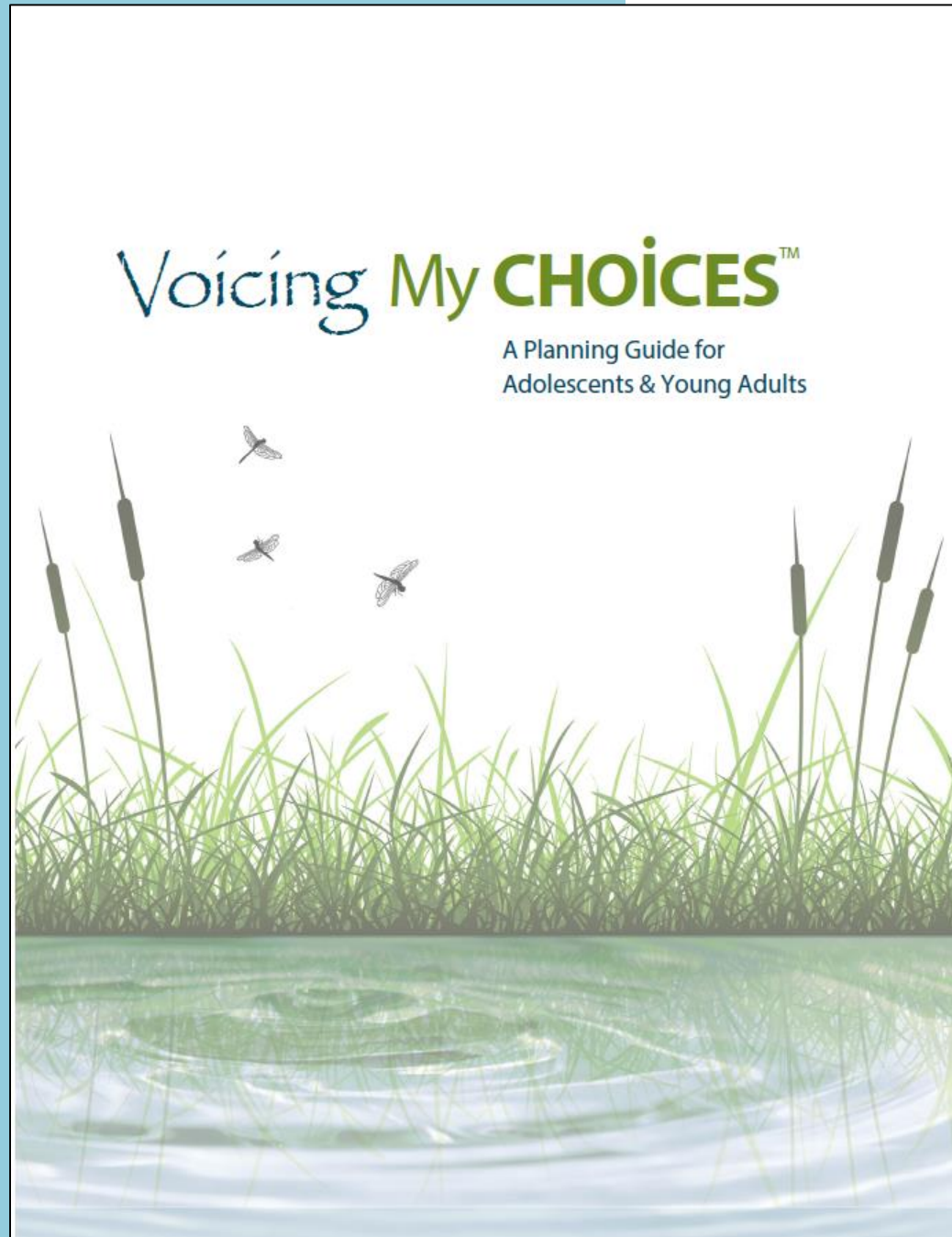
Voicing My CHOICES™

A Planning Guide for
Adolescents & Young Adults



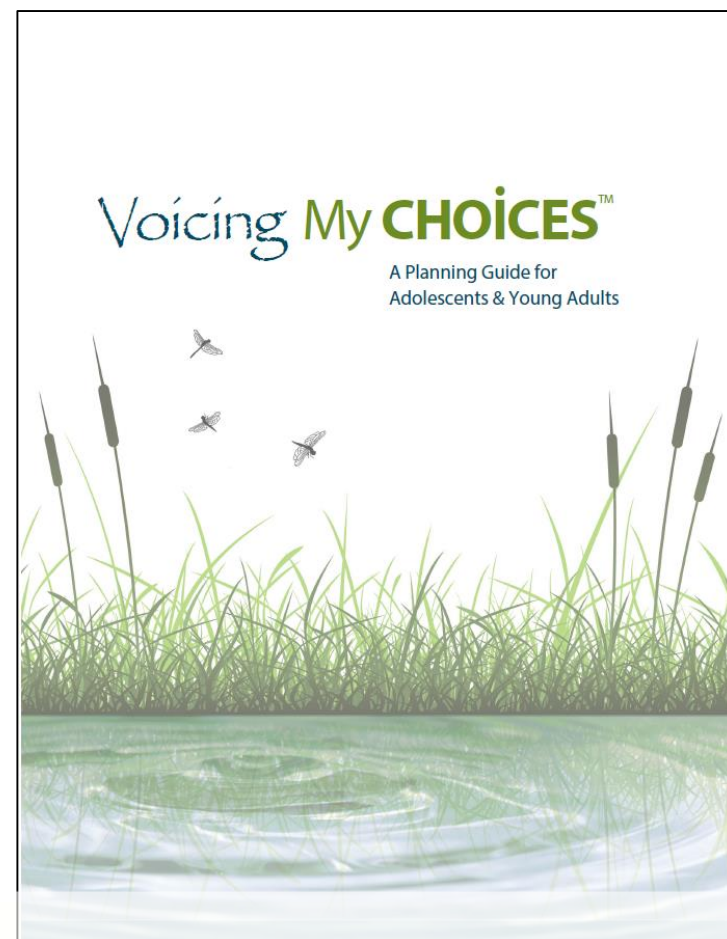


Voicing My Choices ?
translation into Czech by 2 team members
completing VMC by all team members



Voicing My Choices!
VMC team establishment
regular meetings with LW and MW
translation into Czech language
critical revision by 5 PPC team members
piloting VMC among parents

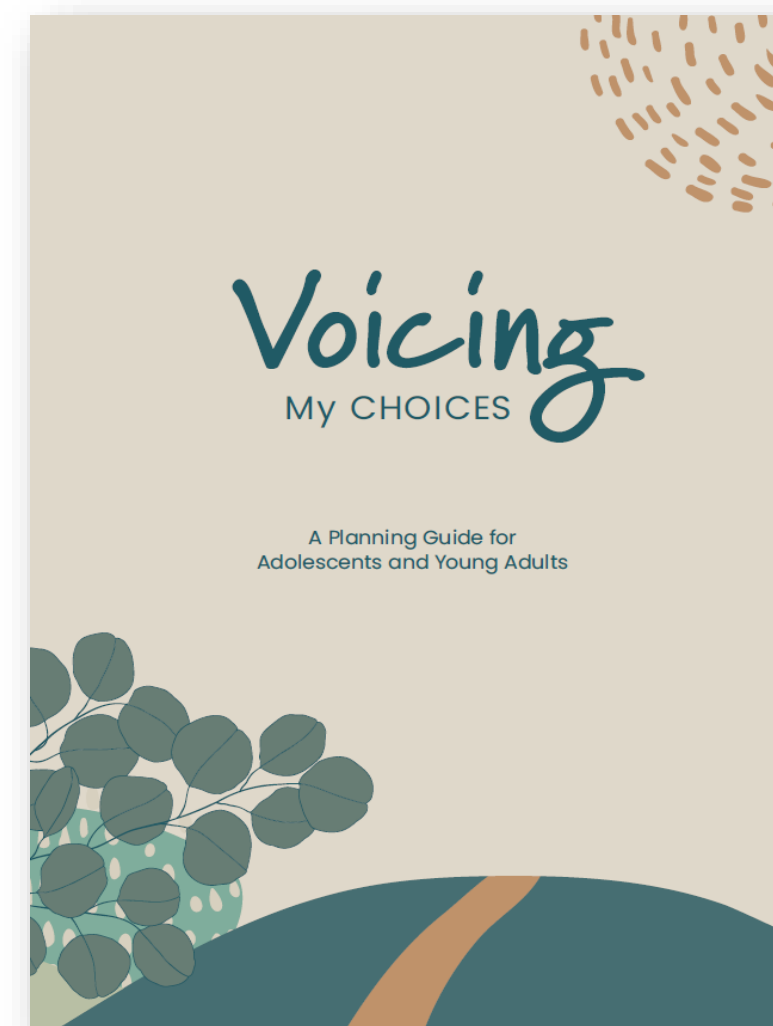
Aging WITH DignitySM



Dando Voz às Minhas ESCOLHAS™
Um Guia de Planejamento para
Adolescentes e Adultos Jovens



UH Motol
official site for VMC Czech version



VMC Czech version
terms not known
fields uncommon



VMC Czech version
terms not known
fields uncommon

religiosity
LST issue



piloting the VMC Czech version among 6 parents 4 children with LLC

boy with recurrent osteosarcoma (age 20)

girl with middle aortic syndrome (age 17)

boy with primary pulmonary hypertension (age 15)

boy with pharmaco-resistant epilepsy (age 13)



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boy with pharmaco-resistant epilepsy (age 13)

- well written, easily understandable
- useful for both parents and children
- may reduce regret
- add “I don’t care” option!



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„That is really very hard reading for a teenager and I guess I need to protect her from the hard stuff.“

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VMC can help AYA's to be heard in a culturally appropriate way



VMC can help AYA's to be heard in a culturally appropriate way

unique communication potential
both challenging and useful
cultural specifics



don't limit
your challenges
Challenge
your limits

next steps
focus groups





Thank you for your attention.

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