What We Can Do When We Don't Know What to Do

Healthcare for People with Down Syndrome During a Pandemic
National Down Syndrome Society

Caring for our Community during COVID-19

• NDSS is the leading human rights organization for all individuals with Down syndrome
• We are committed to providing comprehensive resources to our community during the COVID-19 pandemic
• Visit www.ndss.org to see our in-depth resource list
• Additional Webinars
THURSDAY, APRIL 30
7PM EDT

Coping during a Pandemic

national down syndrome society
ndss®

National Task Group on Intellectual Disabilities and Dementia Practices

National Association of Direct Support Professionals
NADSP

Redwood Coast Regional Center

Making a world of difference in people’s lives

NADD
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NDSS
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NTG Steering Committee member
What NDSS is doing

How NDSS is supporting our community during COVID-19
NDSS Resources

• COVID-19 Hospital Visitation Resource-
  https://www.ndss.org/covid-19-syndrome-visitors-hospitals/

• Call to Action- All Dependent Children Count Act-
  https://www.votervoice.net/NDSS/campaigns/73723/respond

• COVID-19 Survey-
  https://www.votervoice.net/NDSS/Surveys/5777/Respond
What is an Ethicist?

What is our role in healthcare?
What do we do?
What is a Health Care Ethics Consultant (HEC-C)?

Role, Responsibilities and Training

- HEC works with patients, families, surrogates and the medical team to **clarify ethical issues** and **identify values** involved in medical decision-making.
- We **facilitate** discussion, provide **expertise in ethical analysis** and allow all perspectives to be explored in each unique case.
- We promote respect for the values, needs and interests of all stakeholders; **seek consensus** on the goals of care; **mediate conflicts** and **render opinion** and recommendations that are ethically supportable.
- Specialized training through academics, experience, certification (ASBH)
Ethical Principles

Corner Stone principles

- Respect for Autonomy
- Beneficence
- Non-Maleficence
- Justice
Respect for Autonomy

Self-determination

- Privacy, liberty rights (case law: Quinlan)
- Freedom to choose
- Requires:
  - Liberty (freedom from coercion, control)
  - Agency (capacity)
  - Information (adequate to understand)
Beneficence

Acting in the best interest of the patient

- Positive requirement to provide a benefit
- Utility- Balancing the burdens vs. benefits
Non-Maleficence

“Do No Harm”

• Obligation not to inflict harm intentionally
• Includes:
  – Killing vs. allowing natural death
  – Intending vs. foreseeing harmful outcomes
  – Withholding and withdrawing life-sustaining medical treatments
  – What constitutes “harm” in medicine?
Justice

Equality

- Moral and social theories that attempt to distribute benefits and burdens of a social system in a fair and equitable way among all members
- Fairness and equal treatment of all patients
- Protections for vulnerable patients
Why is bioethics important?

Ethical dilemmas in healthcare are “high stakes”

Every patients counts…
COVID-19 Pandemic Ethics

Ethical Framework

From: Patient-centered ethic
    Individual preferences- treatment choices

To: Public Health Ethics
    “Greatest good for the greatest number”
    “Saving the most lives-saving most life years”
    Allocation of scarce resources- protocols/triage
Top Five “Health-related” Considerations with COVID-19
Life is dynamic and somewhat fluid; thus, the information given here is current and accurate at the time of this presentation.

(Ad Source: MyHeritage.com)
NUMBER ONE  Infection Matters
COVID-19 is an emerging, rapidly evolving situation

INFECTION CONTROL!!!!!!

• WASH YOUR HANDS- “How many birthdays are there?”
• Personal Protective Equipment AKA PPE’s
  • Know when, how to use safely (‘don and doff’) and disposal
• PLANNING
• Physical Distancing (not social)
• Cleaning & Disinfectants
  • Know when, how to do safely disinfect often touched surfaces
• Use Technology to Stay Connected
• What do we know about testing?

Self isolation

Patients do not need to contact NHS 111 to go into self-isolation. If symptoms worsen during home isolation or are no better after 7 days, they should contact NHS 111 online. For a medical emergency, they should dial 999

Anyone displaying coronavirus symptoms should stay at home for 7 days from when the symptoms first appeared

If anyone displaying coronavirus symptoms lives with others, all asymptomatic members of the household should stay at home for 14 days

Choose a well ventilated room, and keep away from other household members not displaying symptoms

Do not invite visitors

Groceries or medication should be dropped off on the doorstep by friends, family, or delivery drivers

Double bag waste and put it aside for at least 72 hours, before putting it in usual household waste bin

UK government advice on self isolation is available at: http://bit.ly/ukgovisol
NUMBER TWO  Care of. .

COVID-19 is an emerging, rapidly evolving situation

“Remember the “Airplane Oxygen Mask” directions”

• Taking care of your self
  – Healthy Living (Eating Well, Physical Activity, Sleep, Stress management, Laughter, a Dose of Outdoors)
  – Routines
  – Planning =a sense of control
  – Understand that some things are in and some things are not in your control

• Taking care of your family member
  – Same as above

• BE KIND to others and to yourself... .

Mental Well-being
(Source: SHRM)
Routine (Maintain)
Outdoors (Sun)
Sleep (Rest)
Technology (Advantage)
News (Balance)
Positivity (Try)
Gratitude (Pause)
NUMBER THREE Information Integrity
COVID-19 is an emerging, rapidly evolving situation

JUST THE FACTS, Ma’am

• Reliable Resources
  – CDC, WHO
  – NDSS, The Matthew Foundation, LuMind, AADMD
  – State Guidelines (Overall and departments for IDD)
  – City Public Health Departments
  – Areas Agencies on Aging

• For your family member
• Navigating all these resources!!!!
For your family member with Down syndrome:
A sample

• **Green Mountain Self Advocates** [http://www.gmsavt.org/](http://www.gmsavt.org/)
  – COVID-19 Information By and For People with Disabilities
  – *Coronavirus Plain Language Glossary – Words To Know*
  – *Tips For Working With Support Staff During COVID-19*

• **IASSID**: [https://www.iassidd.org/covid-19-resources/?utm_source=sendgrid.com&utm_medium=email&utm_campaign=website](https://www.iassidd.org/covid-19-resources/?utm_source=sendgrid.com&utm_medium=email&utm_campaign=website)


• **Books Beyond Words** Available for free download at [https://booksbeyondwords.co.uk/](https://booksbeyondwords.co.uk/)
  – Beating the Virus
  – Good Days and Bad Days during Lockdown
  – When Someone Dies from Coronavirus: a Guide for Families and Carers
NUMBER FOUR Life Story
COVID-19 is an emerging, rapidly evolving situation

Who I Am: My Stories, My Meaning, My Life Story

Adapted from Teepa Snow

- **Name I like to be called**
- **The hand I usually use**
- **Living Situations Now & Before** Where was I born? Where did I live growing up and with whom? What kind of a place was it (family, group home or apartment, institution)?
- **Family History & Others** Who are the members of my family? What do I know about them? Do I see them and how often? Do I get letters or cards or visits? How do I think and feel about them? If you had staff, do I remember any special ones, or do I have someone special now?
Any pets?
- **Friend or Boy/Girlfriend or Marriage Now & Before** Who do I like to be with and what do we do? Any past friends who were special? Have I ever been involved in a romantic relationship? What was special about it?
- **Work/Day Program Now & Before** Where have I worked, and do I work now? What do I do at work? Do I like my job(s)? What is job that I really wanted to do but couldn’t? What do I do now during the day and how often?
- **Leisure/Fun Now & Before** What do and did I do for fun and in my spare time? Do I like to “have fun?” What would I like to do if I had the money or time or skill?
- **Spiritual / Religious Now & Before** What religion am I and do I go to services or place to pray or be? How much did or do I do with it? How do I feel about how other people pray? What do I like the best?
- **Personal Care Practices Now & Before** How do I eat? What kinds of foods do I like and what do I hate? How do I sleep? How do I like to get ready for the day; dress, wash, mouth care?
- **Time Now & Before** How do I like to schedule my time? What are my routines? Do I have rituals? What are they? When do I like to do things and when would I like to do things?
- **Important Life Events** What are some things that were very important to or happened to me? Do others know about these events?
- **Anger** What really gets me mad or upset, such as things, activities, and people? How do I show discomfort
- **Calm** What helps me to calm down and relax? What do I do when I get upset? What gives me comfort?
- **Comfort** How do I show distress or if I’m upset or in pain? What gives me comfort?

Don’t re-invent the wheel

Disability COVID-19 Forms
Stony Brook University

https://you.stonybrook.edu/disabilitycovid19forms/2020/04/08/preparing-individuals-with-intellectual-developmental-disabilities-for-medical-treatment-at-hospitals/

My Health Passport
Florida Center for Inclusive Communities

http://fffcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

OTHERS: www.oacbddd.org/covidform
NUMBER FIVE  Advanced Directives
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PLANNING AHEAD: An ounce of planning is worth a pound of cure: ADVANCED DIRECTIVES Giving you some control

- Planning Ahead: Florida Developmental Disabilities Council www.fddc.org
Proactive Planning for COVID-19:

What matters most to you matters to us.
https://respectingchoices.org/covid-19-resources/#resources-for-individuals

- Think about your values and goals
- Reflect upon health care choices you may have to make if you became severely ill
- Choose a person who can makes decisions for you
- Talk to this person about goals, values, and preferences for medical care if you became very ill
- **What is the most important for you to live well? If you were having a good day, what would happen?**
- **What personal, cultural, or spiritual beliefs, if any, do you have that would impact care?**
- **What would you want if you became very ill? For example: Would you want medical care to focus upon: Living longer, maintaining current health, comfort care?**
- **What worries you the most about the situation? What fears do you have?**
- **What else would you want us to know what is important at this time**
What matters most?

PRIORITIES FOR MEDICAL CARE

- **LIVING LONGER**
  - Live as long as possible, even if I do not know who I am or who I am with
  - Be in the hospital and receive all care my doctors think will help me, even if it means relying on machines to keep me alive

- **MAINTAINING CURRENT HEALTH**
  - Live longer, if quality of life and comfort can be achieved
  - Be in the hospital, if needed, for effective care
  - Stop treatment that does not work or makes me feel worse
  - Allow a natural death if my heart or breathing stops

- **COMFORT**
  - Live the rest of my life focusing on my comfort and quality of life
  - Avoid the hospital and being on machines
  - Allow a natural death if my heart or breathing stops
But, in the moment. . .

NICE recommends that the risks, benefits and possible likely outcomes of the different treatment options should be discussed with patients, families, and carers using decision support tools (where available) so that they can make informed decisions about their treatment wherever possible. (Source; BMJ)

https://www.ficm.ac.uk/critical-futures-initiative/care-end-life

- How will critical care treatments help the person in the short and long term?
- Could critical care treatments offer a quality of life that is acceptable to the person?
- Could critical care treatments help achieve a patient’s goals for a good life?
- Are there non-critical care treatments that may help the person and be more comfortable for them?
Other Resources:

- https://adscreources.advocatehealth.com

The real NUMBER One:
What matters the most?
Questions?

You can submit questions/comments through the questions feature.
For more information:

- Visit NDSS.org
- Email Info@ndss.org
- Follow us on social media
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