Palliative Care in Brain Tumor Patients
Maintaining hope from diagnosis to bereavement

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Goals

• Basic understanding of palliative care
• How to optimize quality of life
• Maintaining hope from diagnosis to bereavement
Palliative Care

- Palliate – to make the disease or symptom less severe without removing the cause
- Surgery
- Radiation & Chemotherapy
- Medications
- Physical, occupational & speech therapy
- Counseling
- Meditation
- Complimentary medicine
Why is palliative care important?

- Recent studies suggest that cancer patients who receive palliative care along with standard treatments live longer.
- Good palliative care often leads to improved quality of life.

Survival Analysis

- Median Survival:
  - Early palliative care: 11.6 mo
  - Standard care: 8.9 mo
  - p=0.01

Controlling for age, gender and PS, adjusted HR=0.59 (0.40-0.88), p=0.01

Temel, ASCO 2010, #7509
Palliative Care & Hospice

Treatment directed at the tumor

Palliative Care

Hospice

Hospice

• Large team of providers
  – Physician
  – Nurses or nurse practitioners
  – Counselors
  – Social workers
  – Therapists
  – Trained volunteers

• Home Hospice
  – Care provided by family
  – Agency available by phone 24/7

• Residential Hospice
  – Care provided by facility
  – Nurses and aids present 24/7
Palliative Care

Hospice
Optimizing quality of life

- Set goals
  - Make sure they are attainable
  - But feel free to push the limits
  - Keep them positive
  - Use smaller goals to accomplish a larger goal

Those who remove mountains begin by carrying away small stones
Optimizing quality of life

- Set goals
- Complete advanced directives
Advanced directives

• Legal documents that allow you to declare your wishes in advance should you not be able to make decisions
• Living will
  – Express your wishes on specific issues such as feeding tubes, ventilation, DNR, organ donation
• Health Care Power of Attorney
  – Names a health care ‘proxy’
  – Someone to make decisions for you if you are unable to make decisions yourself
Create an ethical will

• An Ethical Will can be a beautiful piece of you that you leave with your family about YOU.
• It allows and encourages interactive family time through an interviewing process.

• In the Ethical Will you can include things like Family History, Cultural Tradition, Spiritual Values, Blessings, Hopes and Dreams for your children/grandchildren, Life Lessons/Wisdom on Life Experiences, or just a place to answer Special Questions.
Create an ethical will

- What is your favorite food, color, song, music, saying/quote, place to visit?
- Did you have a nickname, who did you get it from?
- What was your favorite thing or activity to do?
- Tell me about a good or bad childhood memory.
- What makes you happy, sad, angry etc?
- What’s your favorite movie/TV show?
- What makes you laugh?
- How tall are you?
- Where do you like to be by yourself?
- What was your first car?
- How did you know you were in love with someone?
- When my mom or dad was born what was your first thought?
- What’s your favorite board game?
- What’s your favorite book?
- Has anyone ever surprised you? How? When?
- If you had a job when you were young what was it? Do you work now, where?
- What is your favorite thing you own
Create an ethical will

- What's your favorite dessert?
- What's your favorite restaurant?
- What did your fight with your brother/sister/s about?
- Do you have a hobby?
- What was your best subject in school? Worst subject in school?
- What is the biggest change you have seen in your lifetime?
- If you could go anywhere on vacation where would you go?
- Where did you grow up?
- What foods do you not like?
- Who's your favorite actress/actor?
- Who's your hero? Why?
- What's the scariest thing you have ever done?
- What's the best birthday present you ever got and who gave it to you?
- What's something you do really well?
- What's your favorite animal?
- If you had a pet, what was it and what was its name?
- What is your favorite season? Why?
- What is the best age to be? Why?
- What is your favorite sport? Did you play sports? What sport/s?
- Tell me about your favorite vacation and who went with you?
Create an ethical will

- What is the hardest thing you have ever done?
- What do you wish you could have done in your lifetime?
- Share and experience you at an amusement park, carnival or fair type place.
- Have you ever been naughty? What did you do?
- What’s the nicest thing you have ever done?
- Tell about the earliest day of school you can remember.
- How did you get to and from school when you were little?
- What was your proudest moment?
- Do you have a favorite phrase?
- What nationality/ies are you?
- Have you ever broken a bone? Where? How old were you when it happened?
- What chores do you hate doing the most?
- What chores did you have to do when you were little?
- What is your favorite thing to do?
- What is your favorite flavor of ice cream?
- Do you have a favorite holiday?
- Tell me about a time you will always treasure.
- What are some things you are thankful for?
- Did you get an allowance when you were little and how much was it?
Optimizing quality of life

- Set goals
- Complete HCPOA, advance directives, living will
- Discuss your wishes and ask questions
Hope

- Wikipedia – “an optimistic attitude of mind based on an expectation of positive outcomes related to events and circumstances in one’s life”

- Merriam-Webster – “to want something to happen or be true and think that it could happen or be true”

- Oxford Dictionary – “a feeling of expectation and desire for a certain thing to happen”
Create a legacy

• Legacy
  – Something you create during your life solely to benefit future generations
  – Often something you never see come to fruition
  – Positive experience
  – Decreases regrets
  – Can be done throughout a lifespan
  – It has nothing to do with money
Art Therapy

• A picture is worth a thousand words
• Self-expression knows no right or wrong
• Allows patients to take their inner experiences and express them in a tangible manner
Art
- Drawing
- Painting
- Handprints
Music
Write
- Letters
- Journals
- Cards
- Recipe book
- Scrap books
- Ethical will
Videos
THANK YOU

Any Questions?

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