Finding & Evaluating
Online Medical & Support Information

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www.lymphomation.org

The views expressed are the results of independent work and do not necessarily represent the views of organizations to which the author is associated.
TOPICS

- Support
- Trust
- Evidence-based decision-making
- Strategic Searching
SUPPORT

The compounding impacts of cancer and cancer treatments on patients and families

Physical | Psychological | Social
The Whole Patient
Impacts of cancer/treatment on patients and families

Physical & Psychosocial

- Physical
- Psychological
- Financial

Impacting:

- Decision-making
- Access
- Quality of life

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (2008)
http://books.nap.edu/openbook.php?record_id=11993&page=1
Jackie writes:

“\textit{I was a complete mess} when I found out I had Lymphoma.

Then I started dealing with it; trying not to \textit{think about it all the time}.

Some \textit{family members} don't even know @ the most maybe 10 are aware I have this cancer.

I might have went about it the wrong way, I feel like I am \textit{losing control now}.”
Variables

- **Cancer type** (risk and natural history)
- **Treatment type** (short and long term effects)
- **Patient status**
  - age*, temperament, skills, health, beliefs, family and social network ...
- **Status of local Health Care system**

* "**older adults** with cancer are more likely to present with a preexisting chronic disease and increased functional impairment and disability, which can compound the stresses imposed by cancer" (Hewitt et al., 2003).
Challenges

- **Outreach**  ability to ask for and find help
- **Navigation**  of highly complex / fragmented health system
- **Communications**  with care providers / insurers
- **Coordination**  among different specialties, nurses, ...
- **Financial**  insurance | billing | ability to work ...
- **Education**  informed partner in medical decision-making
Physical Impacts

Health Impairments

- Disabilities chronic illness, sexual, fertility
- Fatigue and pain
- Cognitive impairment

Compounding psychosocial impacts

“Survivors of childhood cancer similarly have much higher than average rates of chronic illness beginning in their early or middle adult years.” (Ness et al., 2005).
Financial Impacts

- Career / Job / Dependents / Home / Food
- Follow up / Compliance / Supportive care
- Purchase medications / supplies
- Insurance (am I covered)?
- Travel to treatment
- Access to second opinions (best care)?

Compounding psychological impacts ...
Psychological Impacts

- Depression
  - Fatigue and lower functioning
  - Impacts on social relationships / career
- Poor decision making
- Denial
- Vulnerability to Fraud
- Impaired ability to ask for help

Post-traumatic stress outcomes in non-Hodgkin's lymphoma survivors
(Smith SK, Zimmerman S, Williams CS)
Deb writes: “I'm really concerned about important details being missed because you never speak to the same person twice and it seems really hard to get a straight answer when you ask a question.”
Bring List

Bring to all consults:
- Trusted friend or relative
- Referral (primary care doc)
- Insurance cards
- Authorization (insurance)
- Contacts: emergency, other docs, local pharmacy
- Diagnosis, treatment and medical history (concise)
- Medications, supplements, allergies list
- Symptoms / side effects list

Written questions (such as):
- All appropriate options?
- Rationale for recommendation
- Second opinion? | Clinical trials?

First visit / second opinion:
- Pathology report & slides
- Radiology reports / film

Ask about:
- Care managers
- Mental health professionals
- Pain specialists
- Physical therapists
- Nutritional experts
- Social workers / financial help
- Support groups
- Copy of test results
- Next consult / test / treatment?

www.lymphomation.org/bringlist.pdf
Support Resources (example)

Support & Survivorship

Last update: 07/11/2009

TOPICS

Alerts / Keeping Safe | Psychosocial | Doctors | Financial & Insurance | Drugs | Immunization Guide | Treatment Support & Tips | Patient to Patient (right column)

NEW

- Long-Term and Late Effects of Treatment in Adults. [link]
- Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. [link]

Alerts and Keeping Safe

- Consumer Guide on Counterfeit Drugs:
  - how to avoid and report the sale of bad medicines
- Keeping Safe - how to minimize your risk from medical errors
- Health Supplement Alerts

Psychosocial: Emotional / Quality of Life

- Anxiety and Depression
- Books that provide guidance
- Caregiver Stress & Caregiver Tips

Patient to Patient Support | Patient Stories

Art
- Images and poems created by patients and caregivers that portray the experience of living with lymphoma.

Books
- Patient-recommended books on living with lymphoma and its treatment

Caregiver Stress
- Help with identifying and relieving caregiver stress.

Caregiver Tips
- "Buddies" Programs - peer-to-peer support with guidance on How to Help a Friend
Support Resources examples

Government

Non-profit
www.cancer.org  |  www.LLS.org

Professional groups (physicians, other)
www.cancer.net

Peer-to-peer (non-profit - patient/caregiver)
Look for online support forums sponsored/monitored by non-profits or professional groups, although many excellent ad hoc groups exist.
Online Peer-to-Peer Support Groups
consistent moderation & guidelines

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Caveats</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community: I’m not alone</td>
<td>Privacy risks</td>
</tr>
<tr>
<td>Pooled experience</td>
<td>Uneven quality: Error / fraud?</td>
</tr>
<tr>
<td>24/7</td>
<td>Personality or ideological conflicts</td>
</tr>
<tr>
<td>Give, Ask, Participate, “Lurk”</td>
<td>Computer skills / typing?</td>
</tr>
<tr>
<td>News, Clinical trials ...</td>
<td>Too much information</td>
</tr>
<tr>
<td>Good when evidence-based</td>
<td>Anecdotal? Testimonials?</td>
</tr>
</tbody>
</table>

Participation is an very good way for health care providers to learn about and meet support needs.
TRUST

Benefits and Risks of Consulting Online Medical Resources

Red Flags:
Signals of implausible & fraudulent Information
Falsehoods directed to vulnerable:

- "Practicing physicians are intimidated into using regimes which they know do not work"

- "Everyone should know that the 'war on cancer' is largely a fraud’ wrote Dr. Linus Pauling."

Sites/books may falsify risks of standard medicine, then promote “no-risk” Alternative therapies (diet, herbs, etc.)
Experts and Authors?

Danger: persuasive non-experts, media personalities, giving opinion as facts.

Caution: there's the motherly affection for one's idea ... the expected blindness for its imperfections. Author-bias.

Eminence / personality is not evidence

Expert credentials add credibility/plausibility, ... but, human and disease biology is too complex to predict results without clinical testing.
# Bias, Error, and Theft?

<table>
<thead>
<tr>
<th>BIAS</th>
<th>ERROR/CHANCE</th>
<th>THEFT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prejudging?</td>
<td>Poor study design</td>
<td>Intentional,</td>
</tr>
<tr>
<td>Wishful thinking?</td>
<td>Small single-arm study</td>
<td>Misleading for profit,</td>
</tr>
<tr>
<td>Author/sponsor interpretations?</td>
<td>Subset analysis (low power)</td>
<td>Taking advantage of vulnerable</td>
</tr>
<tr>
<td><strong>Conflict of interest?</strong></td>
<td>Not reproduced by independent group</td>
<td>Outright fraud is rare in the peer system / common for Alt Med</td>
</tr>
<tr>
<td>Sponsor media releases</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*In a study design, a bias is defined as an error in the method of study that leads to a deviation in the outcome away from the truth.*
Red Flags

- Conspiracy
- Testimonials
- Treats ALL cancers
- Promoted by ONE practitioner?
  non-doctor, layperson, or doctor working outside field
- Promotional language
- No side effects –
- Natural using preclinical science to support
- No references to published clinical studies

“Good intentions may do as much harm as malevolence if they lack understanding.” ~ Camus
Testimonials?

Verification?
- Truthful? | How benefit was measured?
- Follow up? How long effects lasted?

Clinical details?
- Prior / subsequent standard treatments disclosed?
- Natural history of the disease?

N =1 ... no denominator (not evidence)
- How many did not benefit / were harmed?
- Can’t predict benefit / risk in others

See also [www.lymphomation.org/Testimonials.pdf](http://www.lymphomation.org/Testimonials.pdf)
Conspiracy?

Scientists, doctors, regulators, nurses ... and their loved ones get cancers

Would require the silent complicity of experts, parents, worldwide ... when they themselves or their loved-ones are diagnosed

Detail: [www.lymphomation.org/BigPharma.htm](http://www.lymphomation.org/BigPharma.htm)
Alternative Therapy for Cancer?

- 83 million Americans used it (cancer / other)
- $32.7 billion dollars (1997)
- 425 million Alternative therapy visits, compared with 388 million visits to primary care providers
- 70% to 90% will not mention Alternative therapy visits to their physicians

Journal of Clinical Oncology, Caring (Really) for Patients Who Use Alternative Therapies for Cancer

http://jco.ascopubs.org/cgi/content/full/19/23/4346

Signal? inadequacies of our health care system

The skeptic’s case: www.lymphomation.org/wwlife.htm
Reputable?

- Is it **up to date**?
- Is **author** identified and credentialed?
- Do **several sources** report similar information on topic?
- **... or just one?**
- Are **source studies** cited?
- Is it **biased** favoring product / service they sell?
- Are conclusions based on **case report / testimonial**?

**Reputable physicians** do **not** diagnose, recommend or treat patients online without physical exam.

- Be cautious if asked for **personal health information**.
- **Opinions or testimonials** should be clearly labeled so as **not** to be confused with **fact**.

“**If it’s too good to be true, it probably is**”

Adapted from: Using the Internet for Reliable Health Information, March 17, 2009, Amber J. Tresca, About.com
Evidence-based decision-making

Key Questions | Goal of Therapy
Levels of Evidence
## Benefits / Risks of consulting online resources

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowering</td>
<td>Difficult / complex material</td>
</tr>
<tr>
<td>Could save your life (clinical trial, new approved therapy)</td>
<td>Misinterpretation / lacking broader perspective (gaps in knowledge)</td>
</tr>
<tr>
<td>Fosters shared decision-making</td>
<td>Facing / understanding statistics</td>
</tr>
<tr>
<td>Can reduce risk of medical error, contribute to informed consent</td>
<td>Not recognizing erroneous / low-level / fraudulent information</td>
</tr>
</tbody>
</table>

“Remember that all of our reading is a way of having more productive conversations with our medical providers. So, we can always get them to help us through these judgments too.” ~ Andy M. (advisor)

Adapted from: [www.cancerguide.org/pros_cons.html](http://www.cancerguide.org/pros_cons.html)
Key Questions

- Can it work for me?
- How likely will it work
  - for me
  - in my cancer
  - in my setting (age, stage)
- Is it worth it?
  - Benefits outweigh risks?
- Does it have advantages over available therapies?

Seeking evidence-based information for decision making

- Standards of care?
- Off-protocol?
- Investigational?
Goal of Therapy

Varies widely by cancer type and clinical circumstances

Cure? | Watch & Wait? | Manage as chronic condition? 
Improve Quality of Life?

Depends on

- Type of cancer (high/low-risk) ... natural history
- Widespread / Localized / Where?
- Efficacy of tested protocols (see statistics next page)
- First treatment or Relapsed
- With which approach will I live longer or better (evidence)?
  - Aggressively? Watch and wait? Minimally as needed?

Acceptable risks / side effects:

- Higher for high-risk cancers (vice versa)
Survival Statistics

**not to predict individual outcomes (prognosis)**

Frightening to patients/caregivers

**Limitations**

- Median is a middle point in a range of outcomes
- General, calculated on large groups
- Includes death from any cause
- Skewed by age of population
- Does not account for
  - Recent advances | Individual circumstances

The Median isn’t the Message, by Jay Goulde

[http://cancerguide.org/median_not_msg.html](http://cancerguide.org/median_not_msg.html)
# Levels of Evidence

<table>
<thead>
<tr>
<th>Level</th>
<th>Study Type</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proven</td>
<td>Phase III randomized</td>
<td><strong>Evidence of clinical benefit</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reproducible results!</td>
</tr>
<tr>
<td>Promising</td>
<td>Phase II single arm</td>
<td><strong>Signals of efficacy</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>dose refinements (dozens)</td>
</tr>
<tr>
<td>Plausible</td>
<td>Phase I – dose finding</td>
<td><strong>Dose finding</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is it safe at active dose? (hundreds)</td>
</tr>
<tr>
<td>Starting point</td>
<td>Preclinical animal or cell culture</td>
<td><strong>Activity?</strong> (1 in 5,000)</td>
</tr>
<tr>
<td>Theory</td>
<td>Good science or pseudoscience?</td>
<td>(Infinite)</td>
</tr>
</tbody>
</table>

Types of Studies
focus on clinical

- **Cell culture** only 1 in 5,000 win marketing approval *
- **Animal studies** - starting point rarely predictive of benefit in humans
- **Human (Clinical)** only phase III provide evidence of clinical benefit

*Take home point:* look for hope in clinical-phase studies

* Product Pipeline and Clinical Trials: Bringing a Drug to Market
STRATEGIC Searching

locating evidence-based resources
Abstracts

a condensed version of published study findings

Caveats: Not all that’s published is gold
- The *rush* to publish
- Lacks detail: methods, side effects
- Promotional conclusions?

At a glance: (relevant to me? / level of evidence?)
- Study population? | Big / small? (n) | Clinical or Preclinical?
- Old/new? | Other groups studying? | Where published?
- Randomized or single arm?
- Review article? Systematic is best

Start with PubMed: index of abstracts ...

**Good start:** Provides also links to related articles and full text
PubMed

start here to search abstracts

Published results ONLY
- not commercial sites, press releases, junk science

includes over 18 million citations from MEDLINE
and other life science journals back to 1948


link to full text article and related articles
Treatment Resources

**Standard of Care**

**Clinical Trials - Investigational**
- [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)
  where the preclinical work has already been done

- then search PubMed or ASCO.org:

  **Key words:** Safety, efficacy, mechanism of action

**Other**
- ASH.org (blood) | Medscape.com | PubMed
Strategic Filtering (investigational)

Investigational treatment if needed:
- START with: [www.Clinicaltrials.gov](http://www.Clinicaltrials.gov) then search:
  - Google site search by typing:  
    site:www.asco.org lymphoma  
    site:www.cancer.gov "drug name"

Use dictionaries as needed:
- NCI: [www.cancer.gov/drugdictionary](http://www.cancer.gov/drugdictionary)
## Strategic Filtering (support)

<table>
<thead>
<tr>
<th>Go</th>
<th>Caution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gov</td>
<td>COM commercial</td>
</tr>
<tr>
<td>Edu</td>
<td>Press releases (sponsor)</td>
</tr>
<tr>
<td>Org</td>
<td>Typically more reliable domains</td>
</tr>
<tr>
<td>Non-profits: ACS, LLS other accredited cancer-specific orgs</td>
<td>Phishing?</td>
</tr>
<tr>
<td>(sponsored by credible orgs)</td>
<td>(looks real but isn’t)</td>
</tr>
<tr>
<td>Peer support</td>
<td>Promotional / ads</td>
</tr>
<tr>
<td>Open-source Wikipedia (+)</td>
<td>No references / Red Flags?</td>
</tr>
</tbody>
</table>

### Search

| Sites with Google | site:www.cancer.org *keyword*
|-------------------|----------------------------------|
In Summary

- **the Whole Patient:** there are many urgent needs

- **Trust?** Understanding of scientific method and standards for evidence is lacking in the general public

- **Hope, not Hype:**
  - Best practice: based on type and stage of cancer, goal of therapy, standard of care / investigational ...
  - Red flags: conspiracy, ALL cancers, testimonials

- **Strategic Searching:** Where and how to look
Thanks for listening!

APPENDIX

Supplemental slides & narrative will be available:

www.Lymphomation.org/online-support.pdf