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Cancer Rights: An Overview of Relevant Law
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Meet Abby

- Abby was 42 and had worked at an architecture firm for 2 years before being diagnosed with cancer. Based on a conversation with her doctors, she decided to take some extended time off to deal with her treatment and recovery.

- She told her supervisor, who is also a personal friend, what was going on and her supervisor was very supportive. He even set up an online fundraiser to help Abby with her medical bills. One month into her leave Abby was let go.

- Abby elected COBRA to keep her health insurance. With her savings she was able to scrap together the monthly premiums. Now her savings are exhausted and her 18 months of COBRA are up and she is trying to figure out her health insurance options. She is completely overwhelmed by all of the information on the internet (and in the news) and doesn’t know how to choose a plan other than picking the cheapest one.

Meet Abby, Continued

- Abby has been receiving disability insurance and she is considering trying to go back to work, but she is still suffering from some side effects and has follow up medical appointments that may have to occur during work hours.

- Abby has a large amount of debt as she used credit cards to pay some bills. She is ready to get on with her life, and wants to buy a home, but feels weighed down by her financial situation.

- Abby has been using medical marijuana with a legal prescription, but has been hearing some conflicting information about if this is ok.

- She also doesn’t know where her medical care goes from here now that her oncologist has "released" her.

- Abby feels like she wants to give back and that given her experiences after her diagnosis she wants to fix many of these systems.

How can we guide Abby?
Putting Together The Pieces

The Whole Picture

1. Federal Laws & Programs
2. State Laws & Programs
3. Employer Policies & Benefits
4. Insurance Coverage: Health, Disability, Life, etc.
5. Finances, Medical Bills, & Assistance Programs
Psychological and social problems created or exacerbated by cancer, including:

- depression and other emotional problems;
- lack of information or skills needed to manage the illness;
- lack of transportation or other resources; and
- disruptions in work, school, and family life

cause additional suffering, weaken adherence to prescribed treatments, and threaten patients’ return to health.

Institute of Medicine Report - 2007
CANCER CARE FOR THE WHOLE PATIENT: MEETING PSYCHOSOCIAL HEALTH NEEDS

• 98% of cancer survivors experienced:
  - physical (i.e., pain),
  - emotional (i.e., emotional distress) and
  - practical (e.g., financial, employment) concerns of post-treatment survivorship
• Only 20% of those surveyed got help with their practical concerns
• Number of people NOT getting care for physical, emotional or practical concerns increased between 2006-2010

LIVESTRONG Survey - 2010
Don’t Understand Health Insurance? You Are Not Alone.

• Only 23% understood terms used in their health policy
• Only 50% knew their monthly premium
• Only a few understood acronyms: HMO (36%), PPO (20%) & HSA (11%) (eHealth, 2008)
• When asked to define insurance terms and calculate their bill only 50% got it right (The Regence Group, 2008)

Recent Polls

Has Obamacare been repealed?
• 31% yes
• 49% no
• 21% unsure

• 44% of Republicans said yes
• 27% of Democrats said yes
• 27% of Independents said yes
“Financial Toxicity:”
New Term, Old Problem

2013 - Researchers from Duke:

“Out-of-pocket expenses might have such an impact on the cancer experience as to warrant a new term: "financial toxicity." Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life.”

Contributors to Financial Toxicity

• Health Insurance Status
  • Adequate coverage to minimize out-of-pocket costs
  • Consumer Protections
  • Medical Bills

• Employment Changes
  • To work or not to work - accommodations
  • Disability Insurance

• Life Changes
  • Marriage/divorce, moving, graduating from school, etc.
How Can We Help Catch More People Upstream?

- Education
- Navigation
- Advocacy

Health Insurance Terms

Cost to Have Health Insurance
- Premium – each month

Costs When You Use Your Health Insurance
- Deductible – each year (fixed $ amount)
- Co-Insurance or Cost-Share – each time you get care (%)
- Co-Payment – each time you get care (fixed $ amount)
- Out-of-Pocket Maximum* =

\[
\text{deductible + co-payments + co-insurance}
\]

*usually only for in-network services
Case Study: David

David’s Plan: Deductible = $2,000
Co-insurance = 80/20 plan
OOP Max = $4,000

If David has a $102,000 hospital bill, what does he pay?
1. His deductible of $2,000
   $102,000 - $2,000 = $100,000 left
2. His co-insurance amount of 20%
   20% of $100,000 = $20,000

But OOP max is only $4,000. So, he would only pay the $2,000 deductible + $2,000 of the $20,000 co-insurance amount, for a total of $4,000.

Where We Get Health Insurance

- Insurance Company
- Government: Medicare, Medicaid, Military, IHS, High Risk Pools, etc.
- Employer
COBRA

- Keep employer sponsored coverage
- Cost up to 102% of applicable employee rate
  = Employer amount + Employee amount + 2% fee
- Employers with 20+ employees

States with COBRA statutes:
- AR, CA CO, CT, FL, GA, IL, IA, KS, KY, LA, MA, ME, MD, MN, MS, MO, NV, NH, NJ, NM, NC, ND, OH, OK, OR, RI, SC, SD, TN, TX, UT, VT, WV, WI, WY
- Details vary by state
- Most cover employers with 2-19 employees
- Coverage lasts between 3-36 months
  - Ex: Cal-COBRA = 36 months; Georgia = 3 months

http://Triagecancer.org/StateLaws
Medicaid – Options Prior to 1/1/14

Eligibility: low income + low resources +

- "Aged, Blind, Disabled"
- Breast & Cervical Cancer Treatment
- Minor kids or people with minor kids
- Pregnant women for up to 6 months after baby's birth

Patient Protection & Affordable Care Act (ACA)

Signed into law on March 23, 2010
ACA’s New Health Insurance Option

Medicaid Expansion

New category (door) of eligibility:
• No asset / resource test

<table>
<thead>
<tr>
<th>Household Size</th>
<th>138%*</th>
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</thead>
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<tr>
<td>1</td>
<td>$16,753</td>
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<tr>
<td>2</td>
<td>22,715</td>
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<tr>
<td>3</td>
<td>28,686</td>
</tr>
<tr>
<td>4</td>
<td>34,638</td>
</tr>
<tr>
<td>5</td>
<td>40,600</td>
</tr>
<tr>
<td>6</td>
<td>46,561</td>
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</table>

*Except Hawaii & Alaska

State Medicaid Expansion in 2018

<table>
<thead>
<tr>
<th>Expanded</th>
<th>32</th>
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<tbody>
<tr>
<td>AK², AR⁴, AZ, CA, CO, CT, DC, DE, HI, IA⁴, IL, IN, KY, LA⁷, MA, MD, MI⁴, MN, MT⁶, ND, NH³, NJ, NM, NV, NY, OH, OR, PA², RI, VT, WA, WV</td>
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</table>

<table>
<thead>
<tr>
<th>Not Expanded</th>
<th>19</th>
</tr>
</thead>
<tbody>
<tr>
<td>AL, FL, GA, ID, KS, ME, MO, MS, NC, NE, OK, SC, SD, TN, TX, UT, VA, WI, WY</td>
<td></td>
</tr>
</tbody>
</table>

Updated: 2/12/2018 (information changes frequently, please check for updates)

¹ MI expansion began 4/1/14
² PA expansion began 1/1/15
³ NH expansion began 1/1/16
⁴ IA and AR implemented expansion through premium assistance & wrap around Medicaid
⁵ AK expansion began 9/1/15
⁶ MT enrollment began 11/2/15 for coverage that begins 1/1/16
⁷ LA Governor signed Executive Order for expansion that began 7/1/16
⁸ ME voters approved a proposition 11/17, but the Governor is resisting implementation

http://triagecancer.org/medicaid-expansion
ACA Consumer Protections & Benefits

1. No lifetime or annual limits
2. No rescissions (cancellations)
3. Young adults can stay on parent’s plan until 26
4. Free preventative care (except grandfathered plans)
   - No co-pays, co-insurance, or deductibles
   - Ex: immunizations, blood pressure, diabetes, cholesterol, cancer
   - USPSTF Rated A/B (+ Mammography for women 40+)
   - [Website](http://www.healthcare.gov/coverage/preventive-care-benefits)
      - Colonoscopies AND removal of polyps
      - BRCA genetic screening AND testing
5. Clinical trials

ACA & Health Insurance Appeals

- Denials of coverage
  - Internal appeals (ERISA – employer plans)
  - External appeals (ACA and/or state law – all private plans)
    - State Health Insurance Agency
      - [Website](http://www.triagecancer.org/stateresources)
      - Triage Cancer Webinar on "When an Insurance Company Says No"

If your health plan denies treatment apply for an Independent Medical Review (IMR)

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ACA Health Insurance Rights (after 1/1/14)

1. Premium Rating
   - Individual vs. Family Plan
   - Geographic Location (Ex: CA has 19 regions)
   - Age (64 can only be charged 3 times more than a 21 year old)
   - Tobacco (some states have eliminated this – CA, DC, etc.)

2. No Pre-Existing Condition Denials/Exclusions
   - Insurance companies *cannot* look at:
     - Pre-existing condition (physical or mental) or health history
     - Gender or age

Latest news:
Idaho
Iowa Farm Bureau
Texas vs. US

Short-Term Health Insurance Plans

Short-term plans:
- Should have been eliminated under ACA & don’t have ACA protections
- Can exclude things like chemo
- High out-of-pocket costs, even if lower monthly premium
- Can end mid year
- Does not = creditable coverage or trigger SEP

Review of 45 short-term plans showed:
- 43% don’t cover mental health services;
- 62% don’t cover substance abuse treatment;
- 71% don’t cover outpatient prescription drugs; and
- None of the plans cover maternity care

Latest news:
Awaiting final HHS rule expanding the availability of these plans
ACA Requirement to Have Health Insurance
Most U.S. citizens & lawfully present must have health insurance

What coverage counts?
- Employer or Individual Plans
- COBRA/HIPAA Plans
- Medicare, Medicaid, Veterans Health
- High Risk Pools, & others

How much is the penalty?

<table>
<thead>
<tr>
<th>Year</th>
<th>Adult Penalty</th>
<th>Child Penalty</th>
<th>Family Max</th>
<th>or % of Income, whichever is more</th>
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</thead>
<tbody>
<tr>
<td>2014</td>
<td>$95</td>
<td>$47.50</td>
<td>$285</td>
<td>1%</td>
</tr>
<tr>
<td>2015</td>
<td>$325</td>
<td>$162.50</td>
<td>$975</td>
<td>2%</td>
</tr>
<tr>
<td>2016, 2017, 2018</td>
<td>$695</td>
<td>$347.50</td>
<td>$2,085</td>
<td>2.5%</td>
</tr>
<tr>
<td>2019</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
<td>0%</td>
</tr>
</tbody>
</table>

Latest news: Individual Mandate penalty drops to $0 in 2019
Fine collected through IRS annual taxes

ACA’s New Health Insurance Option

State Health Insurance Marketplaces

- “Exchanges” = insurance shopping mall
- Benefits:
  - Cap on OOP max: $7,350 individual / $14,700 family
  - Financial help
    - Premium tax credits
    - Cost-sharing subsidies
**Marketplace Plan Options**

**Standardized cost-share:**

- **BRONZE PLANS**
  - Lowerest monthly costs
  - Higher out-of-pocket costs when you receive care.
  - 60% Coverage | You pay 40%

- **SILVER PLANS**
  - Higher monthly costs than Bronze plans.
  - Lower out-of-pocket costs than Bronze plans.
  - 70% Coverage | You pay 30%

- **GOLD PLANS**
  - Higher monthly costs than Silver plans.
  - Lower out-of-pocket costs than Silver plans.
  - 80% Coverage | You pay 20%

- **PLATINUM PLANS**
  - Higher monthly costs.
  - Lower out-of-pocket costs than Gold plans when you receive care.
  - 90% Coverage | You pay 10%

**Now may be 66%**

**Catastrophic coverage (under 30 or $ hardship)**

---

**Loss of Employer-Sponsor Health Insurance? Pick a Lane**

- **Lane 1:** COBRA or State COBRA
- **Lane 2:** Marketplace Special Enrollment
- **Lane 3:** Other group plan (spouse or parents)
- **Lane 4:** Medicaid or Medicare?

Trying to fill coverage gap while waiting for marketplace plan to start? Can chose COBRA coverage only until Marketplace plan is effective, but get Marketplace plan first, then COBRA
Comparing Plan Options

- Marketplace Plan
- Employer Plan
- Medicare Plan

Marketplace Plan

Employer Plan

Medicare Plan

Do the Math!

The Math Matters!

Total potential costs for year = 12 months of premiums + OOP max

#1:
- Monthly premium: $120.61
- Deductible: $6,500
- Out-of-pocket maximum: $7,150
- Total yearly cost: $1,447.32 + $7,150 = $8,597.32

#2:
- Monthly premium: $251.08
- Deductible: $2,800
- Out-of-pocket maximum: $5,700
- Total yearly cost: $3,012.96 + $5,700 = $8,712.96

#3:
- Monthly premium: $392.34
- Deductible: $1,000
- Out-of-pocket maximum: $2,500
- Total yearly cost: $4,708.08 + $2,500 = $7,208.08
What are the differences between plans?

- Cost
  - Premium, Out of Pocket, Co-Pay, Deductibles, Cost-Share

- Networks of doctors and hospitals
  - Check to make sure your doctors are covered by the plan you choose

- Prescription drug coverage
  - Which drugs are covered?
  - Is there a separate drug deductible?

Checking Providers, Facilities, & Drugs

Enter your doctors, medical facilities & prescription drugs to see if they're covered by each plan.

You save money by using doctors and facilities (like hospitals and pharmacies) in a plan’s network – and drugs it covers.

Search for and select your doctors, facilities, and prescription drugs below.

See the terms of your health plan. Your plan's network, benefits, and provider list are set by your health plan. If you’re in a health plan, you can choose any doctor in your plan’s network. (Outside your network, doctors and hospitals may charge more than your in-network provider.)

Visit the website to search for your providers and facilities.

Information provided by the insurance companies. Some information may be out of date, and plans change which doctors and drugs are covered during the year. Check with your doctor and the insurance company before enrolling to make sure your doctors and drugs are covered.
Employment Rights

Federal Fair Employment Laws
- Americans with Disabilities Act (ADA)
  • Discrimination protections for patients and caregivers
  • Reasonable Accommodations for patients
- Rehabilitation Act 1973

State Fair Employment Laws
- Discrimination protections for patients and caregivers
- Reasonable Accommodations for patients

Leave Laws
- Family & Medical Leave Act (FMLA)
- State Leave Laws

Employment Contracts
- Employment Contract
- Union Contract

Employer Policies

- Employee Benefits
  • Health/dental/vision insurance
  • Short-term and/or long-term disability insurance
  • Life and/or accidental death insurance

- Other Benefits
  • Sick time
  • Vacation time or paid time off (PTO)
  • Pool of donated hours
  • Flex time/job sharing/telecommuting
  • EAP programs

- Medical Leave or Reasonable Accommodation Process

*Triage Cancer Quick Guides – [http://triagecancer.org/quickguides](http://triagecancer.org/quickguides)
Americans With Disabilities Act (ADA) (Title I)

Enforced by Equal Employment Opportunity Commission www.EEOC.gov

Eligibility:
- Private employers with 15 or more employees
- State/Local Governments
- Federal employees covered by Rehabilitation Act of 1973 (similar to ADA)
- Be a “qualified individual”
- Have a disability under the ADA’s definition (includes cancer)

Applies to all phases of the employment process

Employers can’t make employment-related decisions based on medical info

Benefits:
- Protection from Discrimination
- Reasonable Accommodations

Reasonable Accommodations

“Any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities”

- **Modifying Work Space**
  - Phone, fax, files within easy reach
  - Switching offices
  - Special furniture requests

- **Modifying Schedule**
  - Working from home
  - Part or full-time
  - Flexible schedule
  - Schedule breaks
  - Extended leave

- **Other Options**
  - Use of Technology
  - Change in Policy
  - Shift Job Responsibilities
  - Change Job


*Checklist: Reasonable Accommodations http://TriageCancer.org/Checklist-ReasonableAccommodations
### Employer Size - State Fair Employment Laws

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<td>HI</td>
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<td>ME</td>
<td>MI</td>
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<td>NJ</td>
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<td>CO</td>
<td>WY</td>
<td>CT</td>
<td>IA</td>
<td>KS</td>
<td>NM</td>
<td>NY</td>
<td>OH</td>
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<tr>
<td>PA</td>
<td>RI</td>
<td>CA</td>
<td>ID</td>
<td>MA</td>
<td>MO</td>
<td>NH</td>
<td>OR</td>
<td>KY</td>
</tr>
<tr>
<td>WA</td>
<td>AR</td>
<td>(but 15 for RA's)</td>
<td>WV</td>
<td></td>
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</tbody>
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*If state is not listed, it requires 15+ employees*

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### Family & Medical Leave Act (FMLA)

Enforced by: U.S. Dept of Labor Wage & Hour Division [www.dol.gov/whd](http://www.dol.gov/whd)

- Federal law for:
  - Employees with a serious medical condition
  - Employees with a spouse, parent, or child with a serious medical condition
    - Parents
    - Spouses (common law spouses & same-sex spouses as of 3/27/15)
      - Note: not domestic partners
    - Children (biological, foster, adopted, step, or in loco parentis)
      - 18+ only if "incapable of self-care because of a mental or physical disability"
  - Employer: private employers with 50+ employees and all government employers (federal, state, local)
  - Employee: 1250 hours, 12 months
State Leave Laws

- FMLA type leave for smaller employers:
  - DC (20), ME (15 pvt, 25 public), MD (15), MN (21), OR (25), RI (30 public), VT (15)
- Expanded definition of family:
  - CT, DC, HI, MD, NJ, OR, RI, VT, WI
  - Example NJ: Child, spouse, parent, in-laws, or domestic partner. Does not require spouses to share leave. 12 weeks in 24 months, not to exceed 6 weeks in 12 months
- Expanded use of FMLA leave:
  - CT, ME, MD, OR
- Paid sick leave:
  - DC, CT, CA, MA, OR + Cities – see chart
  - Federal Contractors - EO
- Unpaid leave to take family members to routine medical visits: MA, VT

http://triagecancer.org/statelaws

Disability Insurance

- Short term vs. long term
  - Short term – generally up to 6 months
  - Long term – generally 12+ months
- Private Disability Insurance
  - Purchase through employer
  - Purchase directly from company
- State Disability Insurance
  - CA, HI, NJ, NY, RI, and PR
**INCOME OPTIONS**

- Federal Disability Insurance
  - Social Security Disability Insurance (SSDI)
    - 10.5 million receive SSDI
  - Supplemental Security Income (SSI)
    - 8.3 million receive SSI
- About 65% of applications initially denied

- Triage Cancer Resources:
  - Quick Guide on Disability Insurance
  - Blogs on Disability Insurance

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**Disclosure Rights**

Generally, not required, but may need to disclose some information to use . . .

- ADA's discrimination protections
- Reasonable accommodations
- Medical leave

- Choices about what you share
- Make conscious disclosure decisions
  - Then communicate those decisions
- Long-term impact
- Impact outside of employment
  - Relationships & dating

*Quick Guide to Disclosure, Privacy, & Medical Certification Forms*
Other Cancer-Related Legal Issues

- Medical Marijuana
- Estate Planning
- Medical Decision Making
- Death with Dignity Laws
- Appeals
  - Health insurance
  - Disability insurance
  - Government benefits
- Education Rights
- Family Law
- Medical Bills
- Consumer Law
  - Bankruptcy
- Genetics
- Veterans’ Rights
- Caregivers’ Rights

Abby Revisited

- Abby was 42 and had worked at an architecture firm for 2 years before being diagnosed with cancer. Based on a conversation with her doctors, she decided to take some extended time off to deal with her treatment and recovery. **FMLA, ADA, Disability Insurance**
- She told her supervisor, who is also a personal friend, what was going on and her supervisor was very supportive. He even set up an online fundraiser to help Abby with her medical bills. One month into her leave Abby was let go. **Disclosure, ADA, Loss of marketplace & other government financial assistance**
- Abby elected COBRA to keep her health insurance. With her savings she was able to scrap together the monthly premiums. Now her savings are exhausted and her 18 months of COBRA are up and she is trying to figure out her health insurance options. She is completely overwhelmed by all of the information on the internet (and in the news) and doesn’t know how to choose a plan other than picking the cheapest one. **COBRA, ACA Marketplace, Math Matters, Finances**
Abby Revisited, Continued

- Abby has been receiving disability insurance and she is considering trying to go back to work, but she is still suffering from some side effects and has follow up medical appointments that may have to occur during work hours. **Disability Insurance, Reasonable Accommodations, FMLA**
- Abby has a large amount of debt as she used credit cards to pay some bills. She is ready to get on with her life, and wants to buy a home, but feels weighed down by her financial situation. **Rebuilding Financial Health**
- Abby has been using medical marijuana with a legal prescription, but has been hearing some conflicting information about if this is ok. **State/Federal laws, Reasonable Accommodations, Disclosure**
- She also doesn’t know where her medical care goes from here now that her oncologist has “released” her. **Survivorship Care Plans**
- Abby feels like she wants to give back and that given her experiences after her diagnosis she wants to fix many of these systems. **Advocacy**

What Can You Do to Help Cancer Survivors?
The application of **pressure** and **influence** on the people and/or institutions that have the **power** to give you what you want.

### How the Legal Community Can Engage with the Cancer Community

- Join Health Law Section’s Breast Cancer Initiative ([https://www.americanbar.org/groups/health_law/interest_groups/educational_outreach/breast_cancer.html](https://www.americanbar.org/groups/health_law/interest_groups/educational_outreach/breast_cancer.html))
- Engage in advocacy ([http://triagecancer.org/advocacy](http://triagecancer.org/advocacy))
- Provide pro bono/low cost services to cancer survivors in your community
- Purchase the Cancer Rights Law book!
Cancer Rights Law

Buy online:
www.ambar.org/cancerrightslaw

20% off Discount Code: CANCERRIGHTS20

About Triage Cancer

Triage Cancer is a national, nonprofit organization that provides education on practical and legal topics, beyond diagnosis.

- In-person educational events
- Monthly webinars
- Trainings for health care professionals
- Educational materials
- Animated videos
- International, national, state resources
- Charts of state laws
- CancerFinances.org
- Educational Blog

*All Triage Cancer services are free
*Funded by grants, sponsorships, and donations

http://TriageCancer.org
@TriageCancer
You’re Invited

June 29, 2018
Chicago, IL

https://triagecancer.org/chicago-summer-soiree

Monica Bryant
mb@TriageCancer.org
Http://triagecancer.org

Connect on Social Media
Twitter: @TriageCancer
Facebook: @TriageCancer
Instagram: @TriageCancer
Cancer Rights Law provides an overview of key areas of the law that often come into play for individuals who have been diagnosed with cancer and their caregivers, including health insurance, employment, disability insurance, genetics, estate planning and medical decision making, and finances and consumer rights.

Whether you teach a law school class, run a legal clinic, are interested in forming a medical-legal partnership, want to provide pro bono legal services, are responsible for navigating patients through their cancer experience, or are coping with your own cancer diagnosis, this book will provide valuable information and practical resources to effectively navigate cancer-related legal issues.