**[](http://fionasfamilyhouse.org/)**

Fostering a community of intentional healing and support for young adults with advanced cancer, and their families. It takes a village.

A Case for Community Support

For Young Adults with Advanced Cancer

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A Case for Community Support

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This is an article about cancer; more specifically, this article discusses the largely unaddressed needs of men and women who've been diagnosed with advanced cancer as young adults (ages 19-39). We'll be discussing some of the specific aspects of this group (which we'll refer to as YAs) and suggesting some potential approaches for addressing their unique needs.

# Overview

Life changes instantly, and in a dramatic fashion, for anyone who receives a cancer diagnosis. When that diagnosis is for an advanced stage, metastatic cancer, the upheaval is greatly amplified; when the person receiving that diagnosis is a young adult in his or her prime, the experience is particularly surprising and dismaying. Each year, about 70,000 YAs are diagnosed with cancer in the United States, which represents less than five percent of newly diagnosed cancers in the country. The extremeness of having cancer at that age, the derailment of a normal, young person’s trajectory toward being an adult… they’re at college, they’re finishing high school, they’ve just graduated from college, they may be newlywed. They are not yet rooted in where they are, so when they get the diagnosis of cancer it can be a major derailment.

Because this is such a small percentage of cancer patients, there's relatively little YA focused research and no specialization in issues specific to this population. Clinical trial data, which patients rely on for prognosis and timeline estimates, is almost always from older adults or children, making life-changing medical decisions difficult for YAs because of distorted patient data demographics. As is the case with any distinct group, there are unique challenges and barriers in existence.

It is relatively rare for a young person to be diagnosed with cancer, which means that it's going to be relatively rare for an oncologist to treat a young person with cancer. A typical oncologist in the United States might have one patient enter their her practice in their 20s or 30s every year or two. Compared to younger and older cohorts, there has been a relative lack of progress in the United States in the diagnosis and treatment of adolescents and young adults (AYAs) with cancer from age 15 through 39. Cancer is a leading natural cause of death for this population and the spectrum of cancers that are commonly diagnosed for AYAs differs from older patients.

While survival rates have steadily improved for children and adults who have cancer, improvements in YA survival rates have been stunted. Healthcare professionals who work with this population speculate that the likely reasons for lack of progress in YA survival rates include: low numbers of clinical trials for YAs, delayed diagnosis of their primary cancers, poor understanding of the biology of YA cancers, cost of insurance coverage and out of pocket costs, and limited emphasis on prevention and early detection for YAs.

## Psychosocial and Supportive Care Needs

Young adults dealing with serious disease face unique psychosocial concerns such as: fertility preservation, body image & sexuality, education, insurance issues, long-term treatment effects, and employment reintegration. For example, there's evidence to suggest that there may be something about young women who respond — biologically — in a different way to the tumor and to chemotherapy, compared with older women. However, researchers don't know enough to determine dose variations or protocol differences that are needed for this population.

With the relatively small number of YA cancer cases compared to older adults and children, it is important to note that not every YA or his or her system of support will experience challenges in all of these areas. However, after reviewing the small amount of targeted research that does exist for this population, and soliciting feedback from a random sample of YAs with metastatic cancer, we consider it critical that a model of support be developed to provide targeted support to YA’s.

Furthermore, we believe Santa Cruz County, a community with a history of innovation, openness, and support, along with a robust group of alternative healing professionals is an ideal place to pilot such a project. The concept is simple: in community we are stronger, in family we are stronger, and by imparting knowledge through direct practice and advocacy, YA’s live richer and more empowered lives, gaining strength through their diagnosis.

# Case Study

What follows is the actual story of a young adult living with advanced cancer. While no case is typical, this is an example of what it is like to receive an advanced cancer diagnosis as a young adult. We invite you to imagine this scenario happening to you, or to a young adult you know and love: one of your children, a relative, a friend, a neighbor, or a coworker.

You are a 36-year-old woman, living with your husband of six years and your three-year-old son. You and your husband are living a typical middle-class, young American life, working hard to pay your bills and the mortgage on your first home, and settling into a balance of working, connecting with your partner, child, family, friends, and community. You share household chores with your spouse, spend as much time as possible engaging in meaningful ways with your child, and tend to your home and garden. You’re trying to save money for your future after recently pouring your entire life savings into a down payment for your home. You are in excellent health, eat healthy food, exercise regularly, and enjoy healthy relationships.

Both you and your husband are making good strides in building your careers. You’ve been working at the managerial level for two years, after working in your chosen profession for seven years. You are months away from completing your Master’s Degree program, which you expect will help you to eventually fulfilling your dream of owning your own business. You are considered a rising star in your company, and are widely regarded as a likely candidate for a big promotion when senior staff retires.

One night, you begin to experience cramping in your pelvic area, and after a couple days, it wakes you up in the middle of the night and sends you, doubled over in pain, to the emergency room. A flurry of doctor visits and scans ensue, and within a couple months, you’ve been diagnosed with stage four bladder cancer. Your previous medical appointments as an adult have all been related to pregnancy and childbirth, so dealing with the healthcare system as a patient is bewildering.

Your advanced cancer diagnosis brings with it a bevy of disease-related activities and responsibilities that immediately change your priorities and availability. You soon have the first of many CT scans, followed by the first of your lifelong chemotherapy treatments, having been told you’re incurable. The chemo side effects are disabling for 5-7 days, so your ability to maintain your responsibilities at work starts to falter. You have to teach your very active son to no longer jump on you, and you buy a small safe in which to keep your growing collection of prescription medicines because you fear his natural curiosity could cause him to explore your many pill bottles.

A few months later, you have the first of your 5 anticipated major surgeries. Two liver resections leave with you with a new liver, though new tumors take root there within a few months. Next up is an intensive week of pelvic radiation, which renders you sterile and sends your young body into premature menopause. Then surgery to remove the original bladder tumor, which is only partially successful, and leaves you with an urostomy (a bag that is attached to your bladder and rests outside of your body because you are forever incontinent).

Two years later, having now outlived the median life expectancy for someone in your condition, your life has taken on a very different rhythm. Your average week now includes about 25 hours related to health care management, including oncologist visits, weekly blood draws, hours at the infusion center, weekly lymphedema treatments, therapy, pharmacy visits, daily ostomy management, numerous phone calls to providers and the insurance company, and transportation to and from all of those appointments. Your husband has been remarkably understanding and helpful, but there's only so much he can do, exacerbated by the financial strain because you’ve been unable to work full-time since starting treatment, and your health has now reached a point of having to stop working altogether.

Your son, a joyful and energetic little boy, has been hit especially hard by the loss of time with his mommy; these days, much of his time with you is spent playing while your rest or fall asleep on the sofa. Your husband leaves for work early so he can get home to help with dinner and bedtime, which means that your son (now 5) takes care of many morning chores that his mom used to handle: opening the curtains, taking care of the dogs, making his breakfast, and helping mom get out of bed. Although his behavior has regressed to toddler-like tantrums and wanting to be held like a baby, he has had to grow up more than his peers, due to your fatigue and inability to meet his needs for several days after chemotherapy infusion.

Finances have now become a nightmare. As a two-income young couple, you were able to manage the mortgage on their first home, pay for pre-school childcare (about $1,300 per month), get out with friends occasionally, and enjoy weekend family excursions. Your income has now been reduced to SSDI, which helps cover basic bills, but childcare costs are becoming out of reach, at a time when you are no longer energetically capable of caring for a little one. Your parents help with babysitting when they can, but neither family has the wealth to take care of all of your bills.

Perhaps the biggest financial concern is the cost of healthcare. Your employer-supplied plan has covered you and your son, but that is soon to be gone; moving over to your husband’s policy will cost $600 a month, and then there’s the $10,000 out of pocket per year (another $800+ per month), which you’ll reach within the first month of the insurance year: a single chemotherapy treatment costs about $40,000, so you hit your out of pocket maximum almost immediately. Medicare will eventually provide a solution for your insurance needs; however, there’s a two year gap between qualifying for SSDI and being eligible for Medicare, so paying for health insurance is an unavoidable reality for the next 18 months. You, like many young adults with advanced cancer, have no viable solution to manage your financial responsibilities other than the very uncomfortable reality of relying on donations from friends and family.

To say that family life has been disrupted is a severe understatement. Your husband now comes home from his long workday and manages most of your sons’ nighttime care, household chores, and everything else that used to be mostly shared responsibilities. The strain on him is intense, but his choices are seriously limited, and you worry about his health. Your son thinks of you as a mother who “has always been sick;” he’s seen you go through numerous crises over the past two years. Although he has other adults in his life, managing the enormity of this situation is an incredible hardship for any kindergartener.

A life once focused on career, motherhood, and a fulfilling marriage has now become focused on finding a new purpose, building memories for your son, and learning to live in declining health with grace.

Difficult though it may be, try to imagine this happening to one of your loved ones; it happens more often than almost any of us know. The impact is not always the same, but it is always disruptive and permanently life-altering for all concerned.

# Unique Challenges

Were you able to put yourself in the shoes of the cancer patient in our case study?

It’s not a story we see portrayed in the media: a young mother dying slowly while trying to maintain some semblance of her former life, and hoping that her son remembers her as a person, not a patient. Young adult-onset cancer represents less than five percent of all cancer diagnoses, and of those diagnosed with cancer between 19-39, only 10% receive a stage four (metastatic) diagnosis. Still, it’s more common than we realize, and there aren’t enough resources to support these 70,000 patients diagnosed with cancer in the United States every year, especially given the evidence that YAs need a disproportionate number of psychosocial supports versus their older adult counterparts. There isn’t a model of care for young adults with cancer, though their needs are very different.

Research suggests that YAs are five-times more likely to develop PTSD than their healthy peers, and that at least 30 percent of YA cancer survivors have severe mental health symptoms, even 20 years after remission. The reality is that cancer is a life-altering experience. Those who survive can go on to life fulfilling, meaningful lives; however, life will never be the same. While it is easy to assume that survivors can return to business as usual after finishing treatment, the fact is that most find this very difficult and will almost certainly have a lifetime of varying levels of physical and/or emotional side effects.

## Isolation

Isolation is a key issue for young adults with advanced cancer: finding any peers in similar circumstances is rare, and nearly all support groups and services for cancer patients are geared toward older adults. The level of isolation that young people experience is more than older adults or children who are diagnosed with cancer. They have limited experience with the health care system compared to a child whose parents are most likely involved in care and making decisions. If you're an older person with cancer, chances are you've known other people who've had cancer. It's not as foreign to you as an older adult as it is for someone in his or her teenage or young adult years.

The same can be said about friendships. Unlike older adults, who tend to be familiar with having friends and family members struggling with health crises, healthy young men and women are likely to be bewildered by one of their peers facing a terminal illness. Some of your friends may respond in wonderful ways, while others will quietly and completely drop out of your life.

Online groups and forums are helpful, but the simple truth for people like you is that there’s nobody nearby to whom you can reach out to and trust that they truly understand your circumstances. At the same time, many YAs find it difficult to maintain existing friendships. Peers find it difficult to relate to someone going through treatment, and many haven’t experienced a lot of loss, due to their young age. The following are quotes from YAs about isolation:

“I wish there was a support group for younger people. To my knowledge there aren't any young cancer patients near me. I met the family of one with my cancer, but she died before I could meet her. It is important I think for us to know we're not alone.”

“I have to say, being under 40 with cancer is bizarre for me. Nearly everyone in the waiting rooms of the offices I frequent are old...like 70's, 80's and 90's. The first thing a surgeon told me yesterday was "you shouldn't be here.’ I agree"

When I was going through treatment (when I was 18 and 19), I didn't have the emotional support to cope with issues such as being told I would never have children and dealing with a changing body. Also, at a time when I was naturally separating from my parents, the diagnosis of ALL snapped me right back into dependence on them.”

Cancer can create a sense of isolation from friends and family, who may not understand what you are going through; this isolation is often worse for young adults than other caner patients. As a young adult, it may feel like you are losing your independence at a time when you were just starting to gain it. Perhaps the YA just began college, landed a job, or started a family. A cancer diagnosis puts most people on a rollercoaster of emotions. Moreover, treatment may require hospitalization far from home, which can lead to emotional isolation. A desire for normalcy may keep you from sharing your cancer experience with your healthy peers, adding to a sense of isolation.

## Family Needs

Family needs vary greatly with the YA population. For some YAs, family needs are about their family of origin, while other YAs have moved on and either planned to form or have formed their own family units. Parents of YAs feel alone; losing an adult child is not the norm. YAs are isolated from their peers, and now are in the position of raising children, or trying to maintain their career path, while balancing a rigorous treatment schedule. Other YAs may have been between relationships, possibly dating or planning to spend their forever with a partner.

Young children further complicate matters, especially with the rules of medical institutions regarding children visiting patients, and also with the standard M-F hours of most medical facilities. Childcare is expensive, and added expenses are particularly difficult if the YA has had to put his or her job on hold for treatment. In any of these circumstances, cancer disrupts the expected trajectory of life.

“As the parent of a 7-year-old, I find scheduling frustrating, especially during the summer. My cancer center does not allow children on the 2nd floor, where the infusion rooms and physician offices are located, so if my kiddo is out of school/camp for any reason, I have to schedule my appointments around when I can get childcare for him. And then when the office runs late or I have a slow nurse at infusion, I get stressed about being late picking him up. It would be great if there was a drop-in childcare area close by, especially during the summer. I am always reminded that those of us with young kids are the exception and not the rule!”

“My infusion center has a rule that children under the age of 16 are not permitted in the infusion room. My oldest told me that she envisions me lying lifeless on a table while being drained of life, when a green monster puts medicine in and brings me back. I took her in briefly to see what it was like. I think having a family time where kids can see what happens makes it less scary. Having more understanding of families and their needs would be great!”

“Recently, after spending the morning cleaning up 2-year-old vomit, thanks to a visit from the Vomit Fairy, I took my overly bleached self to have labs drawn. I noted a sign stating “no children allowed,” and come to find out that the oncology center is seeking a national certification that requires no child under the age of 12 be allowed in the "clinical" areas of the building, or be unsupervised. Children 12 and over must be accompanied by an adult at all times. So now I won't be able to take the boys with me for my labs. I can bring them into the building, but they must wait with a responsible adult that I probably should know in advance. I briefly considered paying the first person I saw sitting on a bench, knowing there was a good chance that same person would be sitting on the same bench when I walked out. This has me thinking, what if something medically urgent happened to me while I'm there having labs drawn? What are they supposed to do with my kids? What would happen to my kids if they needed to call 911? How could It would take at least 15 minutes for their father or a grandparent to get there?”

“I am a single mom. My partner left me when I was pregnant and diagnosed with cancer because he couldn’t handle it. I am fortunate that a relative stays with me the week of chemo, but every time they leave it’s a emotional rollercoaster. An overwhelming sensation of stress and sadness consumes me and I weep every night out of the tiredness that comes with a newborn, chemo, heartache and facade of happiness around my kids. I just wanted to sleep, to get away and to rest.”

“I don’t know how to include my partner in my care I adore my boyfriend, and we are very happy together. I would, however, like him to be more involved in helping me make medical decisions, researching new options and discussing life with the (unfortunate) complications of medical conditions. In general, he avoids the topic--which is possible at the moment because my health is stable, and because my mom and friends help me manage everything.”

## Sexuality and Fertility

The estimated number of cancer survivors of reproductive age in the United States is now approaching half a million. Although cancer treatments have evolved to cause fewer harmful side effects in these patients, [radiation therapy](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=CDR0000044971&version=Patient&language=English) and many [chemotherapy](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=CDR0000045214&version=Patient&language=English) agents can still damage fertility. The most frequent cause of impaired fertility in male cancer survivors is chemotherapy or radiation-induced damage to sperm. The fertility of female survivors may be impaired by any treatment that damages immature eggs, affects the body’s hormonal balance, or injures the reproductive organs. This is relevant to teenagers and young adults, who are typically at a stage in their lives in which they are learning about entering into intense emotional and intimate experiences.

Some of the physical side effects of chemotherapy and radiation affect sexuality and fertility, and some of those effects can endure for a lifetime. A young person who is in that life stage is typically very engaged in the world of relationships and possibly sex, but a young person with cancer often just doesn’t feel like engaging with another. This can wreak havoc on existing or potentially intimate relationships. It can be especially daunting for a young couple who were planning to have children in the near future.

“I was diagnosed with Stage IV two months after getting married (I was 32). After chemo and 2 surgeries that got about 98%, it spread to my lungs. My doctors tell me chemo for life. We had wanted to have kids. And now we can't. It's the hardest part for me. I always wonder if anyone else struggles with this. I feel so alone.”

“I tried to freeze my eggs before radiation but I think the chemo already damaged them too much. I'll be on chemo for life too, and worry about finding a husband that can handle all of that. I'm only 28 years old.”

## Employment

YAs may miss out on various significant milestones, all of which have an impact; one especially significant milestone is career development. area that has a long-term impact is employment. A general rule in our country is that what you earn as a person in your 20s predicts what your income is going to be for the rest of your life. So if you start off with a low income because you've had cancer and weren’t able to complete college, and you then have to find any job to pay off medical debt, your future income prospects are likely diminished.

“I’ve been feeling good and want t get a job. What am I supposed to do about revealing a cancer history during a job search? I just had an interview and it was going very well so I asked the interviewer if any employees were cancer survivors (it was for a cancer organization). I had a whole separate pitch prepared in the event I decided to identify myself as a survivor. I know workplace discrimination is rampant against survivors, but maybe a cancer organization would see it as a plus? Anyways, I didn’t get the job and I don’t know where to go for advice. “

“When I get chemo, my bones ache so bad... but I can't afford to miss work. Plus, if I miss too much work I’ll get fired. Who will hire me with cancer?”

These are just a few areas in which YAs have extraordinary needs for support beyond what is typically offered to cancer patients and yet, there is no model for offering additional supports to the YA population.

# Our Proposed Program: Fiona’s Family House

Given that services for YAs are rare, and that we are unaware of any healing community that is focused on this demographic, it is hard for professionals to develop skills or comprehend the complexities that affect this population. We feel it is imperative that the community first learn about the YA population, and then band together to offer personalized services that address the unique challenges of YAs. We believe that community is critical to building an environment to adequately address the vast needs of YAs, and that without an intentional focus on educating community members about the YA population, isolation, family strain, and continued life-long challenges will continue.

In our proposed model, *Fiona’s Family House*, community comes together to address the psychosocial supports that are needed for the YA *and* the family. Our ultimate goal is to serve as a *central center* for healing resources, end of life planning, childcare, respite, family support, friendship, food, and fun. Through strong connections with county-wide medical services, advocacy groups, complimentary organizations, professional training institutions and legal resources, our organization will be a hub for local resources; patients will no longer need to spread themselves thin by traveling extensively to access help and treatment. Ideally, this model will be piloted and then made available as a national model, free for any local community to adopt and adapt as needed.

## It Takes a Village

The idea of living in community, supporting each other, and offering help when there is a rupture in the family system is not common in western culture. In general, as with most capitalist societies, we tend to value independence and don’t often ask for support. While this is the norm in many American families, other countries have more of a tribal culture, where families are supported and loved by multiple older adults, regardless of blood ties. In this setting, families can feel supported by others facing a similar situation, and isolation is reduced.

After a cancer diagnosis, it is typical for a patient to experience his or her natural tribe of friends and family gathering together to provide immediate support. However, this support often fades as time passes and the initial crisis of the diagnosis is over. Unfortunately, the severity of treatment to prolong life does not stop. Life goes on, and the patient needs to be able to participate in his or her life. Management of the disease doesn’t end. It is in this prolonged crisis and extended period of isolation that Fiona’s Family House steps in to support the family undergoing this transformation. A new natural tribe, one that understands the unique challenges, because they themselves are facing a similar prognosis, forms to provide critical and long lasting support.

## Fiona’s Family House (*FFH*) Model

Our model is a three-phase process to make these services available in Santa Cruz County before 2020. Using available scholarly research and patient interviews, we have prioritized services that have an immediate need and will have an instant impact on YAs.

* In phase 1, we will work with patient volunteers and existing cancer resource center staff to create a physician education course, which will be available for use within a year and facilitated by patient and family advocates.
* In phase 2, we will offer grant scholarships to partners serving YAs who have made a difference in Santa Cruz County and their families.
* The final phase is a stand-alone facility, which will serve as a resource and respite home for YAs and their families. This phase will require several years of fundraising and development of relationships with existing services.

We believe that Santa Cruz, a community with a rich history of innovative support services is the right community to pilot this model, specifically the standalone facility, which relies heavily on volunteerism and alternate treatment modalities, both of which are vast in the Santa Cruz Community.

### Mission and Vision

The mission of FFH is to inspire radical change in scope of medical and support services for young adults living with incurable cancer in Santa Cruz County.

We plan to pilot this in Santa Cruz and hope to be the start of a national movement, which addresses the needs of YAs. We are dedicated to creating resources and a community of intentional healing and systemic change for young adults living with an advanced cancer diagnosis, their families, and their children. We intend to alter the scope of services in Santa Cruz County by educating physicians and service providers to enhance their understanding of the unique challenges affecting young adult cancer patients and their families. In time, Santa Cruz County will be known for specializing in the treatment of a growing niche of patients.

Our ultimate goal is to open a central center for healing resources, end of life planning, childcare, respite, family support, friendship, food, and fun. FFH will be a hub for local resources, sparing patients the need to spread themselves thin by traveling all over to access help and treatment. Fiona’s Family House envisions a community that is educated about the gaps in services for young adults with advanced cancer. We want to build a group of well-trained, volunteer/intern professionals who represent multiple specialties and are available to fill the holes of previously unmet needs.

We foresee a day when young adults living with their diagnoses are empowered and able to be active in the meaningful parts of their lives; a day when YAs are supported financially to live free from fiscal debt and undue worry about medical bills and supportive therapies. We will accomplish this by awarding grant funds to those who need assistance, and by opening a center where YAs can rest while children are well cared for and among friends; a place where families can form forever relationships with new allies, and where patients can safely discuss and plan for a future without them. Deep interpersonal transformation happens in this healing space, and needed practical support helps young adults and their families adjust to the new and unexpected trajectory thrust upon them.

### Phase 1: Empower and Inform

In the first phase, Fiona’s Family House is committed to creating a robust physician education patient advocacy project, which will be piloted in Santa Cruz County and then be made available for free to anyone wanting to start a similar project in his or her local community.

Patient and family advocates will create and facilitate training modules that address common psycho-social issues experienced by young adults with cancer, provide resources for their patients, and make medical practitioners aware of common barriers that are unique to this population. We anticipate crea

### Phase 2: Recognize and Support

Second, Fiona’s Family Fund is committed to ensuring that every young adult living in Santa Cruz County with an advanced cancer diagnosis, along with their family members, has the resources needed to live with their illness and without financial worry.

This fund, which was created as a legacy for Fiona by her mom, invites local partners to apply for financial assistance to cover anything that is needed to support the cancer journey of an individual or organization supporting individuals. Examples of requests include: medical copayments, alternate treatment costs, therapy for the family, childcare for children, and so on. Priority is given to patients who have made a difference in Santa Cruz County through volunteerism or other service.

### Phase 3: Resource and Respite Family Center

In the third and final phase, we will open a resource center, which relies on community volunteerism and families supporting each other. In the proven tradition of using a family-home environment as the main intervention (think Hospice and Ronald McDonald House), Fiona’s Family House is a drop-in center where young adults living with their diagnoses are empowered and able to be active in the meaningful parts of their lives. It is a place to rest while one’s children are well cared for and among friends, where families form permanent relationships with new allies, and where patients safely discuss and plan for their altered futures. The center will support and facilitate patients in all aspects of their cancer journey, and will reduce feelings of isolation for cancer patients and their families.

As a hub of resources, Fiona’s Family House will:

* Inspire and facilitate the building of a natural community of support for families affected by young-onset cancer.
* Serve as an intern site for new practitioners, and thus transform the scope of healing services in Santa Cruz County. By offering specialized training, future social workers, therapists, massage practitioners, yoga instructors, acupuncturists and dietitians who volunteer at our center will become uniquely qualified to work with this rare demographic.
* Provide skills-based volunteer opportunities for professionals such as lawyers and teachers to volunteer their time by giving their expertise to a worthy group of families.
* Facilitate succinct and critical physician education about the unique needs of young adults with cancer, which will inform their treatment plans and decisions about care.

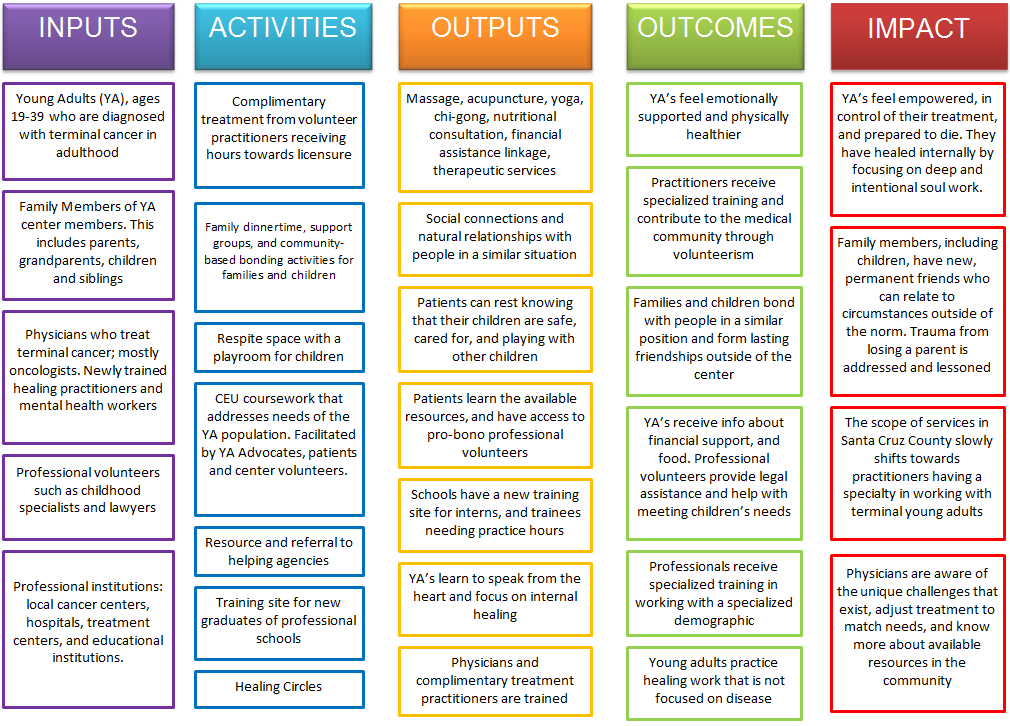
Proposed programs include:

|  |  |
| --- | --- |
| *Patient Practical Support* | Legal advice, body work, respite, healthy meals, support groups, therapy, resource consultation, will/advanced directive, healing circles, benefits consultation, Social Security Planning, and information about reasonable accommodations. All services are intern or volunteer run |
| *Family Support* | Support group, financial planning, case management, wills, legal plan for children, financial resources |
| *Family/Community Building* | Game nights, family dinners, children’s outings, movie nights, YA date nights |
| *Advocacy/Education* | Speak at the local, state and federal level about policy gaps, develop and present a curriculum to physicians; educate community, and provide patient empowerment volunteer opportunities |
| *Internship Program* | Change the knowledge and clinical practice of those in complimentary healing services, arrangements with local schools to offer specialized volunteer internship program |
| *The 29-Month Fund* | Donations restricted to paying for health insurance during the 29 month gap between qualifying as permanently disabled and becoming eligible for Medicare. |

In short, the final phase of Fiona’s Family House is to create a drop in center that is open to any young adult with advanced cancer and/or their family members; family is not defined by blood, but by relationship. Because patients are accustomed to the typically cold and sterile settings of medical establishments, Fiona’s Family House is intentionally configured as a warm, inviting, comfortable home-like environment. We see a one-stop-shop for all services, where everyone who participates is assessed by a knowledgeable social worker, who will act as the lesion between clients and referral services.

#### Outcomes

Outcomes from Fiona’s Family House will provide immediate and short-term comfort to patients and their families, while long-term community change and individual empowerment produce significant transformational impact.



As evidenced by patient testimonials, research, and need, we propose a drop-in center, a family home, and a hub of resources to serve YAs. This program should serve patients, their family members and their caregivers, and should offer the following:

* Encourage patients and their families to meet with and develop lasting relationships with others facing similar circumstances
* Respite relaxation rooms for tired patients
* Supervised play areas and toys for children of patients
* Internship and direct practice opportunities for psychotherapists, acupuncturists, massage therapists, and other professionals to gain expertise (and if needed, internship hours) while providing a needed service to YAs
* Group support and other formats for exploring spiritual issues related to cancer and death for patients and their families
* Community-oriented events to raise awareness of the issues facing YAs
* Physician education, which will inform their treatment plans
* Staff and volunteers who help patients with practical support around serious illness issues such as: financial planning, benefits and disability planning, arranging for quality childcare, determining the best health care coverage plans, and end-of-life planning

While treatment professionals likely receive training in working with cancer patients or with end of life issues, young adult terminal patients have additional complications that are not likely covered in depth and are not part of the standard care discussions at diagnosis. In this model, practitioners learn how to best treat this population and their families, and physicians receive critical education directly from patient advocates. Patients and their families find community, and the entire scope of health and mental health related services changes in the community as more people train.

Cancer patients develop specific training materials for physicians and provide CEU classes to local doctors; in doing so, the patients participate in meaningful work, and physicians are able to collaborate directly in a new and potent way. Ultimately, the scope of medical and cancer support services can be radically altered to properly support young adults who are diagnosed with advanced cancer. And ultimately, patients feel empowered through this collaboration, which can bring purpose to their struggles

Fiona’s Family House exists to transform services for YA’s and to provide the safety net services that are missing from our current system. While gaps are limiting and are often a source of frustration, we believe that by taking an active role in bringing attention to the gaps and connecting with other YA’s and families, the frustration can be transformed into empowerment and purpose. We hypothesize that by offering a centralized home-like environment for YA’s and their families that natural friendships will grow, that deep healing will take place in those friendships, that children will be healthier, that family members will receive more support, that the community and healthcare providers will alter their approach to working with YA’s, and that the unmet needs of young adults with advanced cancer will be minimized. In short, the community is better informed, families are supported, and patients receive critical services, while become advocates for change. Our program addresses the following needs identified in the research:

* Lack of Specialized/Focused Services
* Loss of Friendships
* Employment
* Safety Net Service Gaps
* Family Support
* Health Insurance/Alternative Treatment Cost
* Treatment Schedule/Physician Schedule
* Legal Planning

Fiona’s Family House is a drop-in center for young adults living with an advanced cancer diagnosis, their families, and their children. A social worker is available to provide linkage to support services and to gather information for clients. A referral from a physician or healing practitioner serves as the basis for working with our program. Upon intake, during which our social worker listens to patient stories and identifies individual needs, clients are free to access the home during operation hours. Individual family members will go through a similar intake process and will have equal access to support services.

Volunteer practitioners are available during dedicated hours to provide services in the home. Clients are invited to signup for complimentary treatment as space and time allows. Legal representatives and other professionals will also hold regular office hours for consultation and planning. One room, a quiet room, is available for rest, meditation, stretching, or anything else needed to encourage silent healing. Children are welcome, toys are available, and volunteer childcare providers are available to engage with children while clients receive treatment or rest. The center of our home is the kitchen. Weekly family dinners with all clients provide a time for family bonding and connection with other families in the YA community. Healthy meals are prepared and shared, and leftovers are available to take home and enjoy for anyone undergoing treatment. Children play games and make life-long friendships with children who actually know what it’s like to live with a parent that has advanced cancer.

Patients are trained as advocates who then educate physicians and service providers to enhance their understanding of the unique challenges affecting young adult cancer patients and their families.

More than a drop in center, Fiona’s Family home returns us to a time before independence was the dominant cultural value, when tribes supported each other, and when asking for help (and helping!) was the dominant value/belief system. In this system, which was around just a century ago, people took care of each other, held each other up, and supported each other during times of need. This exists to some extent After the diagnosis, it is typical for the patient to experience his or her natural tribe gathering together to provide immediate support, but this support often fades as the months progress and the crisis of the diagnosis is over. However, the severity of treatment to prolong life does not stop. Life goes on, and the patient needs to be able to participate in his or her life. Management of the disease doesn’t end. It is here, in this vulnerable time period that Fiona’s Family House steps in meet family needs for the duration of life and beyond. Together with other families, also in crisis, a new natural tribe, one that understands the unique challenges, because they themselves are facing a similar prognosis, forms to provide critical and long lasting support.

Staff social workers help young adults navigate the very difficult process of trying to get disability, while maintaining their cost of living, trying to find childcare, referring to financial assistance programs, and determining the most affordable health care coverage plans, and plans that are likely to reduce their share of out of pocket expenses.

Social workers, therapists, massage practitioners, acupuncturists volunteer their time and expertise help patients and their families feel better. Cancer warriors develop specific training materials for physicians and provide CEU classes to local doctors involved, and in doing so the patient participates in meaningful work and their cancer story becomes a story of change. This sense of empowerment and in inspiring change within the medical system through stories of struggle can help heal the patient, not of their cancer, but possibly give purpose to their struggles.

Young adults diagnosed with incurable cancer worry about the future without them, the fate of their children, their partners, their family finances, the impact of treatment costs, their health, and their family. All too often they hear things like: miracles happen, or be positive. We live in a society unwilling to talk about death, especially when someone is given an incurable diagnosis at a young age. Fiona’s House is a place for intentional deep healing, where young adults can process these fears without people trying to fix them. Death and dying are discussed openly and freely, so that they can rest knowing that things have been taken care of. It’s a place to find peace with the process and share philosophies and rituals around death, without judgment and without being told not to worry about death. Fears are validated and discussed, and end of life matters are handled practically by volunteer attorneys, and at a spiritual level through healing circles and therapeutic group and individual work.

Our house environment is ideal for families to meet and bond, and our volunteers are trained to work specifically with this all too common demographic. Relationships are formed early and last for the duration of the crisis and beyond, ensuring a seamless transition. Lastly, practitioners learn how to best treat this population and their families, and physicians receive critical education from directly from patient advocates. In short, the entire scope of health and mental health related services changes as more people train at Fiona’s House and the scope of medical and cancer support services is radically altered to support young adults who are diagnosed with incurable cancer.

# Conclusion

Understand that this is a small niche; however, stats show increasing incidence and lack of services oriented toward YAs indicates a strong need.

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