

step one

clarifying your vision

I am a sailor in my dreams
I travel from land to land
My heart is a compass
I will never be lost.

LIZ ETMANSKI

george's story

Rick's chances were down to one

GEORGE HALL'S life is a paradox. Like that popular movie from some time ago, George has gone "back to the future."

"My wife and I always felt we should be independent with this problem," says George. "Yet seven months before she died my wife said, 'We still haven't done anything about Rick.'"

George's story is a familiar one to parents raising children with disabilities.

"After Rick's birth, my wife and I, well mainly my wife, focused her time and energies raising Rick. There wasn't an infant development program then, you know. A bunch of us parents got together. We helped each other. We started a school for Rick and others like him in the basement of one of the local churches. Nothing fancy, mind you. And we raised the money to hire the teachers and buy the supplies. Eventually we got the government to take them over.

"I was involved in the local association for ten years. For a time I was on the provincial board as well.

"I remember back when someone proposed a Lifetime Friendship Plan. The idea was to pay for friends to look in on the disabled person after their parents died. You see, parents have always been concerned about their children's future. We used to talk about it all the time. What would happen if one or both of us were run over by a car? I used to phone the provincial association periodically to see if there were any new developments. There never were.

"Then my wife took ill and matters really came to a head. We had our Will prepared during that time and we arranged with a trust company to manage the money we left in Rick's trust.

"Still my wife kept saying, 'Isn't there something else we can do?'"

After George's wife died, he was devastated. "As you can imagine it was a terribly painful time. Normally I'm a pretty optimistic person but I confess there were days when my dreams for Rick turned into nightmares.

"I knew I had to do something. Somehow the plans my wife and I had put in place didn't seem adequate now that she was gone. I figured Rick's chances were down to one."

—

This haunted George. Finally, one chilly spring day, he made one of his periodic calls to the provincial association. This time they had an answer. They mentioned the Senior Parents Network led by Jack Collins and Vickie Cammack and suggested he might want to look into it. The Senior Parents Network initiated by the Family Support Institute was simply a group of parents in similar situations. Their common bond was their willingness to search for an answer to this question: "If we were to die tomorrow, what would happen to our relative with a disability?"

George found an instant solidarity with these parents. Their worries were the same as his.

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step one

Clarifying your vision

Remember the old saying: If you don't know where you are going, any road will get you there? Well, we think it's true. That's why, as you begin planning for the future, you need to be clear about what you want. What are you trying to achieve for your relative? What do you imagine for their future? What are your goals? What do you want to prevent? What do you want to maintain? What do you want people to know when they gather to discuss your wishes after you are gone?

Without specific answers to these questions, the rest of your planning will be cloudy and incomplete. Knowing what you want to achieve is the first step in creating a Personal Future Plan.

For most of us, the obvious place to start is by completing our Will and establishing a trust for our relative.

Most of the planning time should be spent identifying what you are trying to achieve, thinking through your goals and objectives, and clarifying your vision. Once these steps become clear, you will be in a better position to evaluate the various options available. Then the technical solutions such as increasing the value of your estate, choosing your trustee, and finding the precise legal clauses will follow. Then—and only then—should you seek the advice of professionals. Your will and estate plan will be more relevant and useful because your directions are clear.

Think of your last plane ride. Did you ask the pilot where you should go? Of course not. You made that decision first. Then you examined the scheduling options and made your decision about price and so on. That's the most effective way to utilize the services of will and estate planning professionals. It saves them time and you money.

Our Experience

•
Family and friends
are the heart
of the matter.

•
An imperfect plan
is better than
no plan at all.

•
Safety and
happiness for
your relative are
the main goals.

•
There are creative
solutions for
every challenge.

george's story

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Their questions were no different from the ones on his mind.

George liked their honesty. He enjoyed their humour. Parents helping parents.

That motivation led this group of senior parents to mount an international search to discover how parents elsewhere were confronting the challenge of creating a secure future for people with disabilities. They collected material from Canada, United States, Australia, New Zealand, and England.

George and the others took the best of what existed elsewhere and spent the next five years developing a new organization which eventually became PLAN.

George was so impressed by the thoroughness of the review that he became a founding board member of PLAN. He agreed with the philosophy: self-sufficiency through member contributions, entrepreneurial fund-raising, and independence from government. As parents who had been promised many miracles during the life of their child with a disability, they were careful not to promise any miracles.

They had two assets. One was their wisdom. They liked to joke that their past mistakes had created enough scar tissue to make them clever. Now they had good instincts. They could smell the mistakes coming. Their second asset was the interest and enthusiasm of a younger generation of parents. By this time the Senior Parents Network had become a full-fledged, parent run, non-profit charitable society called PLAN.

Today PLAN welcomes individuals of all ages and families of every configuration regardless of condition, illness or disability. One of George's peers fondly describes PLAN as the only "condition notwithstanding" organization she knows. George is equally proud that PLAN has become a vehicle big enough for anyone concerned about the future of individuals with a disability.

"We have so much in common. PLAN has provided us with a marvelous opportunity to work together. With that amount of energy, wisdom and talent, no one can stop us." ■

What is a personal future plan?

A Personal Future Plan is a written summary of your plans for the social and financial well-being of your family member with a disability.

We have learned that the most effective question when making a Personal Future Plan is: What is a good life? Families tell us that a good life for their relative should include the following elements:

- caring and loving relationships
- a place of one's own
- choice
- contribution
- financial security.

The worksheets at the end of each chapter will assist you with answering this question for your family's unique circumstances. To download a copy, please visit www.plantoronto.ca and click on the Safe and Secure Worksheets.

The fundamental job of the imagination in ordinary life is to produce out of the society we have to live in, a vision of the society we *want to live in.*

NORTHROP FRYE

What is a vision?

Visions are creations of the heart as well as of the mind. A vision is your description of a desired future for your relative. A vision is about passion—your passion for the future economic and social well-being of your relative. That's why it is so important to address dreams as well as nightmares. Fears, worries, hopes, and dreams are all keys to unlocked passion.

A clear written statement of your vision will help focus your attention. Since a vision reflects your values, your traditions, and your family history, it creates a context for the other components of your Personal Future Plan.

Clarifying and sharing your vision of a desired future for your relative:

- enables you to see the world through your relative's eyes
- invites the involvement of other members of the family
- encourages others to better understand what is involved and gets them thinking as to how they can help
- brings preferred and desirable scenarios into the open
- suggests new opportunities
- moves you forward
- changes the present.

If music be the food of love, play on

GARLAND COHEN was in her eighties when she and her son David joined PLAN Vancouver. She had been pushing the future to the back of her mind for a long time, hoping for a miracle. Garland wasn't afraid of dying; she was afraid of leaving David alone.

David had an apartment in the basement of the house where he and his mother lived for 20 years. While he knew many people in the community, none of them knew one another. Garland's health was failing and she feared that David was growing increasingly isolated and might slip through the cracks.

With the help of PLAN, Garland set up a trust and started a network for David. Soon after, she was diagnosed with cancer. David's network provided the support she needed to die at home. After she passed away, the network helped David move into an apartment of his own.

In the years since Garland's death, David has said that the network gave him a sense of security about living in the community, and that he didn't feel alone. Over time, the network helped him tackle issues like employment, using computers, and going back to school. "They're very wonderful people," he said of his friends, and they said the same about him. John Meyer, an early network member and advisor to Garland in setting up a trust for David more than 12 years ago, observed that if Garland could see how David has thrived, "She'd be tickled pink."

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At the age of 61, when David was diagnosed with brain cancer, his friends rallied round. Weeks later, on a December evening, he and more than 75 others gathered in a room filled with Christmas cheer to celebrate his extraordinary life.

David's dedicated patronage of the musical arts was evident among the guests. Canada's first lady of opera, Judith Forst, related how, for decades, David had been coming back stage after every performance to compliment her. "When David loves something," she said, "it isn't 50 percent, it's 100 percent." Linda Lee Thomas, lead pianist with the Vancouver Symphony Orchestra, said, "A concert of the VSO is not complete without David Cohen. He comes back stage and always has that wonderful hand extended and shares his generous thanks."

David was also well known in political circles. He inherited his mother's passion for peace and social justice, and his letter writing for Amnesty International is legendary. During civic elections, David volunteered his time and rarely missed a local political meeting. At the party for David, Vancouver mayoral candidate Jim Green—out of the country at the time—sent a letter recalling how David's presentation on a panel about the opera, *Of Mice and Men*, moved a tenor in attendance to tears.

Others spoke of David's kindness, the thoughtful way he thanks people, and his generous spirit. Lyle Lexier, a member of David's network, said, "David Cohen has been my friend

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You wait for fate
to bring about
changes in your life
which you should
be bringing about
by yourself.

DOUGLAS COUPLAND

We have learned that sharing your ideas—particularly when you put them in writing—is important. Since you won't be around, it is better to begin the discussion with your other children, extended family, friends, and potential supporters now. Relying on others without telling them could create problems for everyone.

You don't want to assume—as one Mom we know did—that her other children know and understand the complete medical background of her son, only to find that they were too busy growing up to notice, let alone to make notes! Or a Dad who told us that he intends to rely on his next-door neighbours to carry out his wishes for his daughter, without determining first whether they are interested in discussing any of the details with him!

So what are we afraid of?

What keeps so many of us from even thinking about the future let alone formalizing our future wishes for our survivors? What causes our paralysis? Why don't we act? Maybe it's fear.

Love and fear are two sides of the same coin. The coin is called passion. The word, passion, stems from the Greek and Latin words for suffering. Wouldn't you agree that suffering is a mixture of love and fear?

Fear is an intriguing emotion. Fear distorts our perception and confuses us about what is going on and about what is possible. When we use words like can't, ought to, if only, doubt, and impossible, we are under the influence of fear. Fear draws a dark and cold curtain between our intentions and our actions. Like a schoolyard bully, its appearance is deceiving. It's actually more imposing in our minds than in reality.

In our own personal struggles with the issues of future planning and in our work with families, we can identify three schoolyard bullies that everyone must find the courage to confront. We offer them here because we believe that where there is clarity, there is comfort. Where there is understanding, there is the ability to change.

FEAR OF OPENING UP Sharing your hopes and worries means discussing intensely personal matters with others—our spouse, family members, friends or acquaintances, and professionals. This

If music be...

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for 15 years. We talk about opera and human rights and the release of political prisoners and how to end capital punishment.” Longtime friend Owen Underhill disclosed, “I don’t think I’ve ever felt so affirmed in my life as when David left me a telephone message about my work as a composer, a conductor, a father, and a friend.”

Network member Barrie Vickers spoke for everyone in the room when he addressed the guest of honour, “It is a wonderful gift you have given us David, and we’ll live out the joy that you’ve given to us.”

When David took the microphone, he said, “Thank you for your beautiful words.” Then the whole room joined in a rousing verse of Hark the Herald Angels Sing. A long line formed at David’s side, and for the next hour he graciously greeted friend after friend.

Sandra Shields

Post Script

David Cohen passed away peacefully and surrounded by friends. Some of his friends smile in relating how very fitting that the end of David’s life should fall on Mozart’s birthday—amid magnificent musical tributes. PLAN Vancouver staff shall miss David’s daily phone calls that kept everyone up to date on current events and local performing arts schedules. As one of the people on David’s network remarked, “He had a good life and a good ending. Really, what more could anyone ask for?”

Life is full of dying;
life is full of death.
When the reality of
death strikes,
it reminds us of our
physical limitations,
and of the depth
of our spirit.
We may have
regrets and yet
be thankful that
we have a
new beginning,
an awareness that
while we are in
the shadow of death,
a new life has begun.

DAVID KUHL, M.D.

may be awkward. We may need to contact people who have never demonstrated any interest in our relative. Or we may not know who to turn to or who to trust. And we risk rejection.

We've grown up believing in self-sufficiency. We've taken our responsibilities seriously. We've tried all our lives to make sure others wouldn't have to shoulder our responsibilities. We've done the best we can.

With future planning we have to share our hopes, our dreams, our fears, and our anxieties with others. We need to ask others to:

- help us with our planning
- carry out our wishes after we are gone
- believe in our relative and the possibilities for their future.

To do this, we need to reach out. We need to know who we can rely on. After all, what good are your plans if no one else knows about them? Sure, they could read about your wishes in your Will. But will the readers get the complete picture? Will they know what you really want? What if they have questions? Maybe they aren't interested? How can you be sure you will be understood?

FEAR OF DEATH Death is not a popular topic in our society. Even a cursory look at the popular media suggests that our culture is obsessed with youth, living forever, and avoiding sickness and infirmity. An illusion is offered: We can cheat death. While it may not be stated, the implicit message is that diet, exercise, and medical intervention will keep us forever young or forever alive. As Margaret Mead said of our culture, "When people are born we rejoice, and when they're married we celebrate, but when they die we try to pretend nothing has happened."

The fear of death is there for all of us. It lurks just beneath the surface, never quite deep enough, though, to be ignored. Perhaps it presents itself as anxiety, perhaps as an awful sense of impermanence, perhaps as loneliness. We may harbour the belief that parents who have sons and daughters without disabilities have fewer anxieties about death than we do. Not true. Perhaps what separates us from

Statistically,
100% of the
shots you
don't take
don't go in.

WAYNE GRETZKY

those parents is our need to address the future of our relatives not just for our lifetime, but for their lifetime.

For younger people, death can feel very remote. Even thinking about it seems perverse. But death is inevitable and is a natural part of life which we all have to face sooner or later. The Dalai Lama says there are two ways we can choose to deal with the prospect of our death: we can ignore it or we can confront it. Confronting and accepting our own mortality spurs us into action. We gain the wisdom to accept the inevitable and the knowledge to realize that it's better for everyone if we think about—and as importantly—begin to organize our affairs.

FEAR OF MAKING A MISTAKE, OR FEAR OF NOT BEING PERFECT

Now here's an irony for you. In thinking about the future, many of us feel we need to create the "perfect" plan. We are afraid that we haven't covered all the bases. Somehow we think we can make the future perfect even though the day-to-day doesn't always turn out the way we planned.

According to financial and estate planners, lawyers, accountants, and everyone else involved in the future planning business, the most common excuse for not making a Will is the fear of not getting it right. Indecision can paralyze even those with the best intentions. In trying

Our own collection of top ten reasons for NOT preparing for your future

1. The future is uncertain. Better eat dessert first. SARAH LEE
2. I'm afraid that if I make a Will, I will die. JOE AVERAGE
3. I never think of the future. It comes soon enough. EINSTEIN
4. I'm not afraid to die. I just don't want to be there when it happens. WOODY ALLEN
5. I don't see any dark clouds on the horizon. There's nothing to worry about.
GENERAL CUSTER, U.S. CAVALRY
6. I've developed a new philosophy—I only dread one day at a time. CHARLES M. SCHULZ, PEANUTS
7. Dying is a very dull and dreary affair. I intend to have nothing to do with it. SOMERSET MAUGHAM
8. The future is not what it used to be. PAUL VALERY
9. I have seen the future and it doesn't work. ROBERT FULFORD
10. The future is made of the same stuff as the present. SIMONE WEIL

Thoughts on putting it off

- We're not in crisis yet. We still have loads of time.
- The process is too costly, both financially and emotionally.
- I don't know who to turn to. My community of support is too small.
- I'm worn out from too many previous battles. I just need a break.
- We're still young.
- The future is too hard to contemplate.
- I'm a procrastinator. I have a reputation to live up to.

to make perfect decisions, we risk indefinite delay. Perfection equals postponement. Doing our best is as perfect as it will ever get.

Plans evolve

Future plans will change as circumstances change. It takes time for your dreams to evolve. You can always update and revise your future plan. In fact, you should expect to make changes along the way. We all get wiser as we get older don't we? You can expect to gain insight and pick up tips.

Who among us can predict the future? Can we anticipate all eventualities? Here's a simple exercise: Place yourself twenty years in the past. Would you have predicted the 20th anniversary of the destruction of the Berlin Wall? Barack Obama as President of the United States? The threat of global warming? The careers of your children? The size of your nest egg?

To put it another way: have you ever made a decision without having all the answers? Would Columbus have set sail? Would Mother Teresa have moved to the slums of Calcutta? The truth is that we often have to proceed as best we can without all the answers. Hindsight is the only guarantee of perfect vision.

Reflections on having a personal future plan

- It's fair to other family members. They now know what's going on.
- My worries about outside interference are gone.
- I'm better prepared to face the unknown.
- I've done the best I can.
- I've left a legacy of love.
- I'm at peace.

Worksheet 1

After you're gone: clarifying your vision

It's the day after your death. Describe what a safe and secure life will look like for your relative.

List ten words to describe a typical day for your relative, in the best of all possible worlds.

Use some key words to describe your worst nightmare for your relative after you're gone.

What is the most important message you want to leave your relative with a disability? _____

What do you want your survivors to help with after you've gone? _____

When your executors/trustees meet, what do you want them to do first? _____

What are the three priorities you want future caregivers to remember about your relative?

1. _____

2. _____

3. _____

What are the important arrangements you've made to ensure a good life for your relative? _____

How do you want to be remembered by your relative? _____

Worksheet 2

A family portrait

Use this worksheet to develop a portrait of your relative as it will be an important record to pass on to your survivors.

Health

List names of current doctors, specialists, and health practitioners: _____

List current health concerns: _____

List current health treatments: _____

List current health precautions and alternatives: _____

Briefly describe key features of medical history: _____

Education and work

List current educational and/or work activity: _____

What are their future dreams in this area? What other possibilities would they like to explore?

What are some highlights from your relative's school experience? What did they like about it?

What didn't they like about it? _____

Who are the people from the past that your relative had or still has a close connection with?

What are some highlights of your relative's work experience? What did they like about it? What

didn't they like about it? _____

Housing

Describe current living arrangements: _____

What are some future housing options/possibilities for your relative? _____

Summarize previous living arrangements: _____

What did your relative like about them, dislike about them? _____

Who are the people who had a significant relationship with your relative in these previous living arrangements? _____

Leisure and recreation

List current social, recreational, cultural, artistic, and athletic activities: _____

What are your relative's interests and preferred activities in these areas? _____

What are some future possibilities in the area of leisure and recreation? _____

What does your relative most like to do? _____

Personal

How would you describe your family's beliefs and values? _____

What customs and traditions are important in your family? _____

Is spiritual and religious worship important for your relative? Is this an area that could be explored further? _____

What are the significant events, markers or milestones in your relative's life? _____

What brings comfort and peace to your relative? _____

Who has been your relative's greatest source of emotional support? _____

What does your relative gain the most pleasure from? _____

Who are the most significant people in their life? _____

What are their favourite possessions? _____

Worksheet 3

A letter to the future

The last wishes of family members are honoured and respected in our society.

A letter to the future is your opportunity to tell your survivors how you would like to be remembered, and how you would like your relative with a disability to be cared for.

This is not an easy letter to write. Think of it as the letter you might write in the middle of the night when you can't sleep. Be frank about your hopes and fears. Tell those who will survive you what's most important to you.

Dear _____,

With love,

