

## Service, Support and Success

# The Direct Support Workers Newsletter

## The Normal Heart Supporting Love and Romance within Service Systems



By: Desmond Bailey (Vita Community Living Services)

She is a woman who is in touch with her feelings and emotions. She likes to laugh and smile. She enjoys meeting her boyfriend at social gatherings. They are magic on the dance floor. They dance, they kiss, they share a drink, they talk and they giggle. She enjoys having a boyfriend. She loves the feelings she gets whenever she is with him. She feels happier; she feels she belongs; she feels safe; she feels special; she feels like a woman. She wants to see him; she wants to be with him. She wants to enjoy his love and romance. She asks, and asks often, about how she can show him just how much she loves him. She wants to learn about romance, but some of her staff believes that to answer the questions is to encourage sexual behaviour.

He has a boyfriend whom he loves dearly. His face lights up with a big grin whenever he speaks of his lover. He is young, energetic, outgoing and kind. He desires to love and be loved. He is a hopeless romantic at heart; he likes to hold hands with his partner, and walk the malls or sit on a bench in the village and share an ice cream with his partner. He hopes for a relationship filled with love and romance. When he asks questions about love and romance, many of his staff become uncomfortable, some think that he shouldn't be 'allowed' to be gay, others think that he should be encouraged to spend his energies elsewhere doing something 'wholesome.'

### ***Love is a friendship caught on fire.***

*Bruce Lee*

This article is going to talk about romance and love and 'valentine feelings,' not about sex. Inasmuch as human services has taken, and in many places are still taking, time to get used to the idea that people with intellectual disabilities are sexual, there is precious little written or spoken about romance. Sex, yes there are lots of curriculums for that. Masturbation – here let me show you this video. Disease prevention – take a look at these brochures full of pictures of scary sores. But, love and romance ... wait, don't you want to see a masturbation video? Dave Hingsburger once said, "In all my years working in the area of sexuality and disability, I have never once been asked a question to which the answer is, 'penis goes into vagina.' The questions I get are 'How do I get a girlfriend?' 'How do I know my boyfriend loves me?' 'How do I show that I love someone?' We need to start teaching about the anatomy of the heart rather than simply the anatomy of the body.

Maybe this is an area of service that we have not given much thought. Whether gay or straight, every person has the desire to love, be loved; to romance and be romanced. Most of us will determine when

and how we pursue romance. Unfortunately, for some people with disabilities in care, it's not so simple. Some people with disabilities who are in relationships find themselves lacking when it comes to romance due to the mindset, attitudes and beliefs that exist in human services. The nice thing is, when attitude is the problem, a change in perspective can make a huge change in the quality of life for others.

## Romance Defined

***Being deeply loved by someone gives you strength, while loving someone deeply gives you courage.***

*Lao Tzu*

Romance can be defined as 'doing something meaningful, special and unexpected for someone.' It is a sincere gesture to show your love and appreciation for another person. 'Romance' should be an integral part of every personal relationship with no exception for people with a disability. It addresses the need for validity, reassurance, attention and belonging. 'Romance' creates warmth and leaves a long-lasting smile in one's heart. It does wonders for the human mind, body and spirit. 'Romance' brings feelings of contentment and unspeakable happiness and joy. It enables wellness and longevity. 'Romance' is an element that fuels relationships and keeps the fire burning. 'Romance' enlightens, it makes the eyes sparkle, it makes you laugh, and it makes you cry. 'Romance' brings feelings of appreciation and acceptance. It allows you to feel wanted and loved. 'Romance' comes from a genuine place, and speaks from one's heart to another through thoughtfulness, emotion, love and action. 'Romance' reaches the deepest depths of a person's emotional needs. A relationship with romance and passion is like a flower with sunlight and water. It causes continuous bloom and exudes the fragrance of love.

This is what has been denied for so long to people with disabilities.

***I was born with a tremendous need for affection, and a terrible need to give it.***

*Audrey Hepburn*

I trust that we all agree that romance and passion in a relationship contributes to healthy living and does wonders for the person and the relationship. Therefore, consider the following questions: How is it that romance and opportunities for romance evade so many people in our care? How is it that education about romance is not as prevalent in our teachings as other areas of necessities? How is it that conversations about romance aren't part of the norm as they should be in supportive settings? Community living, without argument, is the better option when looking at the past and the way people with a disability used to live. But somehow, with all our good intentions to offer and provide the best care and support, we sometimes get caught up in the aspects of care that address the environmental, practical and administrative needs of the individuals. We fix what we 'can see,' and the internal needs which are also important elements of wellness such as, the need to connect with others, the need for romance, the need for emotional communication, the need to feel belonging and the need for relationship security are sometimes missed. Let us include 'support with love, romance and relationships' in our plan of care for people with disabilities by looking at ways in which we can encourage and offer support with romance in these relationships. To do so, let us examine six key areas:

- Romance and inclusivity,
- The conversation,

- Changing of mind sets,
- Looking at our norms – personal, systemic and environmental,
- Looking at universal romantic gestures and symbols,
- And looking at practical and simple romantic ideas.

## Romance is Inclusive

First, we must come to the realization that romance doesn't confine itself to simply one way of loving. The romantic needs of same-sex couples must be seen as equally important as the romantic needs of opposite-sex couples. We must be careful that personal values do not prevent us from doing what is right. It's unacceptable that, in the community, same-sex couples with a disability may need to suppress their love and feelings for each other for fear of punishment or rejection. The freedom to express love and experience romance is one that we need to embrace.

## The Conversation

I will take the risk and assume that 'romance' is not part of the conversational norm, as it should be, in supportive settings or in community living at large. In the 1980's a female hip hop group emerged on the scene called 'Salt N Peppa.' One of their hit songs was entitled "Let's talk about sex." During that era, it was uncommon for people to talk about 'sex' openly or have those lyrics in songs. Now-a-days 'sex' is something that people can talk about, learn about, not be shy asking questions about. 'Salt N Peppa' helped change the norm. So then maybe we can change the trends in community living – let's 'talk about romance' for people with disabilities. Let these conversations become part of the norm. Let us include individuals in care in these discussions. Let us remove the taboo factor from 'romance and disability', and make it a practical norm. Romance is an important element in any and every relationship including people with disabilities. Let us listen to their romantic dreams and inspirations. Let us offer support to make it happen. Whenever you are offering 'support with romance,' consider following – the 'H.A.P.P.Y' model:

- **Have** those conversations and add talks about romance to the conversational norms in the environments.
- **Ask** the individuals in care, how you can offer support.
- **Plan** for privacy.
- **Plan** with the individual, and
- **Yes**, it's ok for people with disabilities in relationships to enjoy romance and have romantic lives.

## Changing Mind Sets

The primary barrier to any kind of change is the way we think. On the other hand, the way we think can also be the road to success. As Direct-Support Professionals, we need to ensure that we examine ourselves keenly. We are trusted to provide support to individuals in our care. We must ensure that we do not allow the influence of our unstated rules, values and personal norms to interfere with the intrinsic romantic needs of the individuals we support. Remember our thoughts determine our actions and our actions affect the lives of the individuals in our care. It is important that we evaluate ourselves

individually and collectively. The demographics of Direct-Support Professionals are diverse in areas of our values, beliefs and culture. We must ensure that ‘the culture of support’ is consistent with the ‘culture of the need.’ Which means, the support that is administered and the manner in which it is administered, must be consistent with the individual needs of the person being supported. Direct-support professionalism and culturally-competent care are the cornerstones for exceptional service delivery. Providing support with romance is culturally-competent support.

## Personal, Systemic and Environmental Barriers

Sometimes we want to do the right thing, however, systemic, personal and environmental barriers do not allow it. Direct-Support Professionals, when considering ‘support with romance,’ start by assessing the possible barriers: financial, environmental, social, belief, policies, or lack of that may exist. Talk with your team and department heads and address situations that may prevent people with disabilities from experiencing love and romance. Take action and make those systemic and personal changes. We must ensure that the organization is supportive whenever Direct-Support Professionals and the individuals propose support plans for romance. The system must also ensure that it has clear written policies that will ensure that same-sex couples are respected and given the same opportunities, rights and privacy as opposite-sex couples. Zero tolerance for homophobia must be upheld.

### **What You Can Do**

What follows next is a brief look at romance and romantic ideas. None of this is groundbreaking – for you. But remember that people with disabilities have not had a typical history. They were often forbidden anything but brief furtive, hidden, relationships. They often did not have normative experiences wherein they could explore the rituals of love and romance – dating, proms, first kisses and adoring parents snapping photos of young love. What we need to do is think about the kinds of things that people who are in love do, and then begin to teach the men and women we serve about how to show love and caring. The ideas that follow can be your starting point for a ‘beyond sex’ discussion of relationships.

## Universal Romantic Gestures and Symbols

***I like not only to be loved, but also to be told that I am loved.***

*George Elliot*

Universal romantic gestures and symbols are simple acts and simple tools that are used to convey a message of love and care. These gestures are cross cultural and are practiced and accepted universally. People with disabilities can be supported to use these tools to add romance to their relationships. Direct-Support Professionals must ensure that the individuals take the lead in decision making. Our role is to provide support and resources only as needed. We are Direct-Support Professionals; we do what we do from a place of genuineness, thoughtfulness and understanding. The following is a list of some universal romantic gestures and symbols – it’s not an exhaustive list, so be creative and come up with some of your own:

- **A spontaneous kiss:** A spontaneous kiss on the cheek or on the hand, tells the story for that moment. It says, “I am glad you are here, and I would rather be at no other place than with you.”

***For it was not into my ear you whispered, but into my heart. It was not my lips you kissed, but my soul.***

*Judy Garland*

- **A gentle whisper:** A gentle whisper in the ear saying “I love you.” This unexpected gesture will allow your partner to feel loved and appreciated. It will allow him or her to feel safe in the relationship and may even ease stresses and anxieties.
- **Give a compliment:** Giving a compliment will allow the partner to feel noticed. It will build confidence and feelings of appreciation.
- **Develop an endearing name or ‘pet’ name for your partner:** Using an endearing name allows the partner to feel like ‘one in a million.’ They are the only one existing in your realm of love.
- **Give a card:** Giving a non-occasion card tells your partner that you care and shows that you are thoughtful. Don’t wait for calendar dates such as birthdays or anniversaries. Give a card at anytime. It’s worth more when you make your own and write your own thoughts.
- **Send a hand-written note:** Hand-written love notes are as timeless as time itself. It never loses its touch and effect. If you want your partner to “forget-you-not” and wear a smile all day, send a hand-written love note.
- **Giving a rose or flowers:** A rose or a flower never fails to brighten someone’s day. It shows thoughtfulness. The sender will certainly be appreciated.
- **A red rose:** According to poets, a single, red rose means “I love you.”
- **Rose petals:** Rose petals create a romantic ambiance on a dining table during a romantic dinner, in a bath, or when petals line the path to a romantic setting in the bedroom.
- **The color red:** Red, cross-culturally, is the most common colour associated with love. Whether it is a red rose, candles, or personal garments, red is the colour of choice.
- **Drawing the ‘heart’ shape on a homemade cake:** It symbolizes that your hearts belong to each other and beat as one.
- **Chocolate:** It could be the choice for many women; men love it too.
- **Music:** It sets the mood and sometimes expresses your feelings whenever you can’t find the words to say. (Love songs will do, however, instrumentals say more than words).
- **Low and dim lights:** Low and dim lights allow you to feel that only the two of you are in the universe, all you see is each other. Dim light provides a sense of calm and attentiveness.
- **Candy:** Candy says ‘you are so sweet.’ Giving a person candies is a simple way to say I love you.

## Practical Romantic Ideas

***If you want to be loved, be lovable.***

*Ovid*

These ideas are for indoors and out. What will make these moments special, is the privacy and respect the couples are shown. Always plan for maximum privacy; and ensure that utmost dignity is at the forefront with plans for romance. If walking in the community, Direct-Care Professionals should walk a fair distance behind. If at the movies, sit in a different row and away from the couple. Ensure that you are not listening in on conversations. While having private moments at home, ensure doors

Ensure that you are not listening in on conversations. While having private moments at home, ensure doors are closed and, if possible, plan for other residents to have an enjoyable out-of-home event.

### 'Fall' in Love

One of the most enjoyable times to go for a walk is during the fall season. Plan an afternoon walk or a wheelchair stroll in the park during high fall. Wear identical scarves and mitts, if possible, hold hands, shower each other with leaves, and admire the beautiful botanical garden-like setting.

### Starlight or Candlelight

There are several ways to enjoy the stars. Invite your partner to come over, sit on the verandah and enjoy star gazing while having a drink and a snack. Or play a game of who can locate the biggest or brightest star. Or just sit under the brightly lit sky and enjoy each other's company. Plan a candlelight dinner. Inside, on the balcony or in the backyard is ideal and is a classic favourite.

### Movie Night Out

Watching a movie may seem random and predictable, but it can be made into an event. Any date can be wonderfully romantic. Elevate the excitement with dinner and/or a rose.

### Hotel Stay

Planning a romantic overnight stay at a hotel would certainly be a hit for any couple. Sometimes these ideas seem out of reach only because it is not thought of. When put in perspective, it isn't difficult at all to plan these ventures. There may be challenges, but things can work out. A romantic hotel stay would be a great experience that any couple would love. Make it special with rose petals, champagne, music and a room-service dinner.

### Romantic Couple's Getaway

Some organizations plan cottage vacations for individuals where groups go on vacation with staff support. How about planning a couple's weekend getaway? Or a couple's vacation? How awesome would that be? Ensure the location and setting is ideal for romance, plan for maximum privacy, ensure it is scenic with a lake view or a sunset view and plan for couples activities.

### Couples Night Out

From time to time, Direct-Support Professionals from different residences can work together and plan couples events such as: couples night out; couples dances; couples restaurant dining; couples movie night and so on.

### Walk the Boardwalk

Inviting a partner to spend an evening walking by the lakeside or on the boardwalk is a great way to enjoy each other's company.

### Bakes and Cakes

Invite your partner one afternoon to do 'bakes and cakes.' It's romantic and enjoyable whenever partners participate in making pastries. They will certainly have fun.

### Movie Night at Home

Once more, this does not have to be boring and predictable. Make it special by having his or her favourite treat, favourite tea, flavoured popcorn, favourite movie, and share a sofa and blanket. A 'date night in' can lead to interesting possibilities.



### Give a no Occasion Gift

Surprise your partner with a wrapped present. Write on the tag (Because I love you).

### Know Your Partner

Listen to your partner, get to know her and surprise her with something that she has always wanted or something she desires. She will never for get your thoughtfulness.

### Have a Dinner Visit

Invite a partner for dinner. Ensure there is candle light, dimmed lighting and music. Ensure that the environment does not have the hustle, bustle and distraction of other people. If there are other people living in the same residence, plan a community outing to ensure the couple has privacy when possible.

### Work on an art Project Together

Arts and crafts is a fun way for a couple to spend time together. Couples can work on a scrap book to document their precious moments. They can also paint on a canvas or make personal cards for themselves, family or friends.

### Take a Class Together

Couples can also take a class together – yoga, dancing, cooking, baking or any area of interest. Sharing common interests will give the couple something in common to work on and something to always look forward to. They learn the same skill and can be supportive of each other. This is great for conversations and opportunity to spend quality time together.

## OK, Let's Get Practical

So what do you do with all that you've read so far? It's nice to know that "roses are red," but how do you take that knowledge and turn it into action? Well, as a result of thinking and talking about romance while researching this article, a couple of ideas came to mind and it was surprising how easily a couple of "ideas" became "reality."

As Valentine's Day is coming up, we have sold out a "limo night for couples." We've arranged for a make-up artist to volunteer her time to do a makeover for the women and the men will be taught about sprucing up for their ladies. They will then all be picked up at one of our programmes by a limo and driven through the city on a scenic route to a restaurant where they all have reservations. After dinner the limo will pick them up again and drive along the lakeshore on the way home. This idea hit big. All of those who have bought tickets are excited and really looking forward to their time together. This was surprisingly easy to put together.

A woman who makes and designs cupcakes has volunteered to teach a "cupcakes for couples" class. This will be an activity that the couples can do together and each will design cupcakes for their partners. Again, all it took was the energy involved in turning "what if" into "why not?"

These kinds of activities will hopefully have two outcomes. For people with disabilities, there will be opportunities to simply have romantic times and create loving memories. For staff within the agency, it will be a practical demonstration of our commitment to LOVING relationships. Both of those things are worthy achievements.

## Conclusion

To conclude, hopefully this article provoked your thoughts and you are now planning to have a conversation with the persons in care about ways that you can offer support with romance. Maybe now you are poised to make a change and add a new element to your support responsibilities. Imagine living your life without a meaningful relationship; then imagine your relationship without romance; then imagine a person with a disability, who is in a relationship without romance and without having the opportunity to experience romance. We need to challenge organizations, heads of departments and Direct-Support Professionals to begin offering 'support with romance' by having those conversations.

Many couples with disabilities are living in healthy successful relationships. However, it is not enough for people to merely exist in their relationships. It's not okay for people with disabilities to live a life devoid of romance and opportunities to experience the feelings, satisfaction and fulfillment romance brings. Like a seed that is sown needs nutrients and minerals for it to bloom into a beautiful flower, so too does a relationship. Relationships need acts of love, romance and romantic gestures in order to flourish and bloom.

Romance shouldn't be seen as an unattainable luxury. Unfortunately, for some couples with disabilities it does, partly because the subject is not widely talked about or encouraged in supportive settings. Well, this can change and change begins with you. Imagine the joy, imagine the happiness whenever a couple with a disability finds and experiences romance and passion. As Direct-Support Professionals, we have an important and trusted role. Let's use it well by encouraging and offering support with romance to the individuals in our care. It is our responsibility.

### **About The Author**

Desmond Bailey began his Career at Vita Mens Sana in 2000 as a Direct Support Professional, in Residential and Adult Day Services. From there he began to provide support as a Behaviour Technician. Desmond's current role as 'Learning You' - Program Lead where he has the opportunity to work with a staff team that provides education and training for individuals with disabilities. Desmond values his role and responsibilities as a professional in the service system and endeavors to continue to make a difference. He can be contacted for more information at [dbailey@vitacls.org](mailto:dbailey@vitacls.org)

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