

# The Way, the Truth and the Boat

A book about Faith and Light

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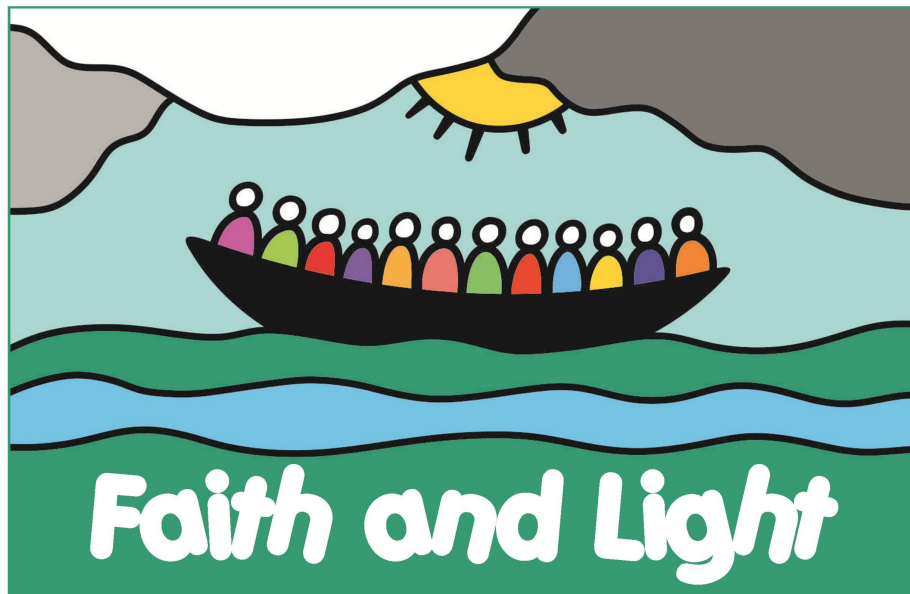
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## 1. Faith and Light

How can you describe the feeling of not being seen as the one you are, the experience of being different and not belong? How can you tell about a movement that affects so many people's lives with a sense of belonging, love and meaningfulness? How can one explain that it is precisely those weak and despised in society who have so much to give, who can teach us how to be completely dependent on God, and to love each person as they are?

We who have contributed to this book are members of the Faith and Light groups in Sweden, Norway and Denmark. It is a collection of stories by relatives of the disabled, of the disabled themselves and of those who join as friends in the groups. Each chapter is a piece in the jigsaw-puzzle, which together with the others gives an idea of what Faith and Light is. We would like to tell you what this movement means to us and how it many times has meant that life turns, when you find a loving community where you are loved and accepted as you are. This book is the result of a desire to spread knowledge of Faith and Light, so that more people will be able to share this movement, which means so much to so many.

There are endless examples of this. For example Amalie Wassberg in the Bethlehem group in Copenhagen, says: "I received a lot of support from Faith and Light when my guinea pig died. I received no support anywhere else. When I'm in Faith and Light, I forget all the demands and problems for a while. Here I am just myself, and the others see me like who I am. I feel free and 'normal'."

Her sister Elisabeth Wassberg explains: "In Faith and Light there is a lot of love and tolerance. There I meet new friends who see me for who I am, and I do not have to be ashamed of my autism. I think it's great and rewarding to have friends from other Christian denominations or from other countries. All the worries of everyday life almost disappear when I am together with the others in Faith and Light. I can always find someone to talk to if I have problems, or someone who can pray for me if I'm having trouble. We are all in the same boat. Faith and Light is the best thing that has happened to me."

A mother in Zimbabwe says, "People around me could not appreciate my daughter

Belinda, but thanks to Faith and Light, they love her today, because the members of Faith and Light have shown that they love her. This is the work of God. Such a relationship would be impossible without the work of God."

Father John from the Netherlands asked at one point Franco, who is disabled, about prayer. When Franco then laid hands on Father John and signed him with the sign of the cross on his forehead, he felt very strongly how God was present in Franco.

Peter from the United States says this: "When you have a disability you can not find friends, then we need to meet in a community and help each other and pray together. I like to meet my friends. Faith and Light is a family of friends who are near God. We do not think of our disabilities. We are like everyone else, because there is no difference. "

And then Anne from France: "Sometimes I wonder how I managed without Faith and Light!"

### **The boat**

Imagine a boat. We are there in the boat - you and me and the others. We travel together. The sun is shining and the water is still.

Jesus is also in the boat. We can not see him, but we trust that he is there, because that he has promised. You can also say that Jesus *is* the boat. It says in the Bible that it is in him we live, move and have our being. He says that if we remain in him then he will remain in us.

Now there are dark clouds in the sky. It starts to blow and the waves go high. We are stuck in the boat. We are afraid, everything feels insecure and dangerous. What shall we do now? We will never handle this!! This is the end!

Then we hear someone who says, "Do not be afraid! 'Though the waves of the sea are roaring and swallowing, I'll be with you' ". Jesus is here! Oh, what a relief! How could we forget it? He has promised never to leave or abandon us. Whatever happens, we are in his hands.

The boat is the Faith and Light log. It is painted by Meb, who was mentally handicapped. In the boat there are twelve figures and Meb said Jesus is lying there sleeping, but we do not have to be afraid because Jesus is watching over us. Meb must have received his inspiration from God - he could not count! This is what he said: We are in a boat and we travel together. Sometimes the sea is still, sometimes there are great waves. Sometimes we must row and sometimes the wind blows in the sail. Meb had understood everything.

The picture reminds us that Jesus is the Way, the Truth and the Boat.

### **What is Faith and Light?**

Faith and Light was founded in 1971 by Jean Vanier. It is a Christian movement for people with intellectual disabilities, as well as their families and friends. The movement is international and today there are around 1500 groups in 83 countries. The groups consist of people of all ages and from several different Christian traditions, such as Anglicans, Lutherans, free churches, Catholics, and Orthodox. Despite our different backgrounds, we feel unity with each other, because it is around Jesus we gather.

Faith and Light is dependent on many active and enthusiastic laymen who spend time and commitment to lead the groups. At the headquarters in Paris there are three employees, but apart from that all work is done voluntary. In each group there is a chaplain who usually has no responsibility, but is there as a friend pointing to Jesus.

## **What do you do in a Faith and Light group?**

Faith and Light groups meet most often once a month, to share joy, sadness and fellowship. The groups consist of between 15 and 40 people of all ages; mentally disabled, with their relatives and friends. Anyone who is open to loving his fellow human being as they are, is welcome to join as a friend in the group.

In Sweden today, 2018, we have five groups. They are located in Uppsala, Stockholm, Floby, Gothenburg and Lund. When you want to start a new group, you must first meet for some time, to find the form and get a stability. Once accepted as a true Faith and Light group, you can celebrate it with a big party!

Through our material, Guidelines, we have a common foundation which ties us together. Throughout the world, we do almost the same things based on the theme of the month, and based on the needs and abilities in each group. The gatherings may differ slightly between the groups, but this is what we do in the group in Floby:

We sing a lot and gladly, preferably songs with movements. Dance is also a standing feature - we dance with our colorful flags, we dance out to the coffee break and we always end with a dance. David loves when we sing, and dances a few turns extra around the ring on his own. Even Elenor likes to sing the songs and moves smilingly back and forth.

We use our flags to praise Jesus and express our joy. The flags are Wilgot favorites. He waves them cheerfully, and of course it sometimes happens that some flags break at some point because of the energetic waving. But it does not matter. The important thing is that we do something together, and that everyone knows that they have a place in the community where they are accepted as they are.

Bible drama is an important element when we meet. Anneli helps us for example to make the text about the good Shepherd come alive - everyone are sheep and the shepherd walks before us to the green meadows with fresh water. So nice to get around and baa and feel the confidence of being close to the Shepherd. But then one sheep disappears. Everybody is looking for it. Finally we find the sheep and everyone is happy! We rejoice, sing and dance. In Faith and Light, a drama is not just an act - we are actually in the story, live in it, play and experience everything that happens. Here's something that we can not find in ordinary congregations, where people often are inhibited by comparison and shyness. Here we can take off the masks and become as children again.

The fellowship is important and therefore we let the coffee break take some time, to hang out and talk to each other. In many groups you also play games and have creative activities. If there are anyone who have had a birthday since we met last, then we sing and cheer for them.

We conclude with a prayer time. Johannes lights the candles on the altar, and then we send around a candle light and pray for God's blessing over each one. When the light comes to Klara, she is quite still, as if she can feel the holiness of God's presence. We rest in silence. Jesus is here.

Then we say goodbye by singing "*May the road rise up to meet you....And until we meet again, may God hold you in the palm of His hand.*" When we say goodbye, we're already looking forward to meeting again!

Sometimes we go on a trip somewhere, and in the summers we have a camp together with the other groups, which for many is the highlight of the year.

## **What is so special about Faith and Light?**

The most important thing is that we want to do something together where we all can feel fellowship and belonging. Everyone can be as they are and contribute with what they can. It is not that some are there to help the others. We are there on equal terms to give to each other and to build relationships.

Our society today is characterized by efficiency and performance. One should be good, one should succeed, and many times people with disabilities are outside. But we find that our disabled friends have a lot to teach us, not least about love. We all have the same value, and have the right to be loved and accepted as we are.

For many Faith and Light has become a place where you can grow together in love with God and fellow human beings, but also a place of support and understanding. It is where you find community and friends, and a social context where you feel important.

## **Do we need Faith and Light in Sweden?**

Marie Bräutigam writes on Faith and Light's Swedish website: "Do we really need Faith and Light? There are lots of other groups meeting, socializing and drinking coffee. Can we add something that other groups can not do as well?"

In many countries, disabled people's families do not get the practical and financial support given in Sweden. In these countries, Faith and Light has an important practical function. But in Sweden we have adapted accommodations, personal assistants, daily activities, travel services and good facilities such as rollator walkers and wheelchairs, so in this area Faith and Light has nothing to do in Sweden.

In many other countries, Christian inspiration from Faith and Light means very much for people with mental disabilities and for their families. But Sweden is a secular country where many people are uninterested of religion. Some people see religion as a threat, something we definitely should not push on to other people, least of all disabled people.

So is Faith and Light really entitled in Sweden? Do we have something to give to people and to society that other groups does not have? Yes! More than ever, we are needed in today's society. Faith and Light touches and changes people's hearts, giving joy and hope in difficult life situations. Faith and Light is a precious pearl. "

## **Core values**

Here are some of our values, compiled by Father Josef Larsen, former international clergyman in Faith and Light:

♥ The community is important in Faith and Light. At each meeting we want to give time to talk and to listen to each other. Then it's important that we get personal ties to each other and see each other's gifts and suffering. We get to know each other as the unique people we are, and we become loved and respected as we are.

♥ The heart is the center of compassion. Love to our neighbour gives us compassion. We want to help those who suffer, heal the sick, and preferably remove it. Often we can not do this. Compassion helps us to feel solidarity, being close to the one who suffers, though we can not remove the difficult one. Such compassion Jesus showed when he became one of us. Such compassion is found in Faith and Light.

♥ In Faith and Light we like to have fun. Having a party is part of the regular program for each meeting. We dare to be spontaneous and we sing, play, dance and are a bit crazy. We bring out the child within us and show genuine joy. Jesus himself invites us, because he

often compares the Kingdom of God with a banquet. Faith and Light has the task of showing the church a liturgy that has more heart than brain.

♡ We can not take away all suffering, but we can be close to those who suffer, be there, join in, embrace. We do not need to be strong, we can show our own uncertainty and sorrow. We can share suffering, bear each other's burdens.

♡ We are created in God's image. The soul lives in the body, regardless of what the body looks like. Therefore, we should consider our own and others' bodies with great reverence. When Jesus washed the feet of the Apostles, it was with reverence and humility. It is our duty to look at ourselves and others with loving eyes and having loving hands.

♡ Many people in Faith and Light are very fragile, and many disabled people are unable to take care of themselves. Some of us can be fragile but it's not visible on the outside. In Faith and Light we learn to trust in God. Jesus shows us how we can surrender to the Father. Our task is, despite of the suffering, to be a sign of joy.

♡ Imagine how the world could be if we all were loving and trustworthy to each other! In Faith and Light we practice this. Friendship and community are keywords. We trust each other, entrust to each other, listen and give each other time. We dare open ourselves. Faith and Light shows God's presence in our time, shows that Jesus is among us. Faith and Light changes lives.

### **How did Faith and Light start?**

The story of Faith and Light began in 1968, with a family with two disabled boys, Thaddée and Loïc, making a pilgrimage to Lourdes in France. It was not an easy trip for them. At the hotel they had to eat their food in their room, because the other guests thought it was offensive to see when the boys ate. The family felt that people turned away to avoid seeing them.

When they returned home, they contacted the special teacher Marie-Hélène Mathieu and Jean Vanier, and with them they were given the idea of arranging a pilgrimage for the disabled, and then three years of preparations began. They organized groups, chartered aircrafts, formed healthcare groups, booked hotels and planned programs.

In 1971, they made the first pilgrimage to Lourdes for disabled as well as their families and friends. It became 12,000 pilgrims from 15 countries!

The trip was a fantastic experience and afterwards they felt that they would like to continue in some way. Jean Vanier suggested that they continue to meet in small groups. "Do what the Holy Spirit is leading you to do," he said, and so Faith and Light started.

### **Who is Jean Vanier?**

Jean Vanier was born in 1928 in a Catholic family in Canada. He first worked as a marino officer, later studied philosophy and theology, and taught a time at a university in Toronto.

In 1963, he visited his friend, the french Dominican monk Thomas Philippe, who was the priest of a small institution for the mentally disabled in the village of Trosly-Breuil outside Paris. He became very grasped by Father Thomas's friendship with the disabled. Father Thomas asked: "Can you do something for these people? Maybe you can start something new? "

Jean loved teaching at the university, but he also knew that God wanted something else for him. In France, at this time, there was also a screaming need for homes and workplaces for people with disabilities. In 1964, he made another visit to his friend outside Paris. That's

when he decided to do something. He started visiting institutions for mentally disabled. "They were terrible places, full of noise and violence, and yet I was marveled. I thought I heard a cry in these men: 'Do you love me? Will you come back?' What he saw and heard just confirmed his call. That same year, he completed his career at the university and bought a small house in the village of Trosly-Breuil.

He had previously met Philippe Seux and Raphael Simi, both of whom were mentally disabled. Now they moved from the hospital to live together with Jean Vanier in a fellowship. Jean called their home L'Arche (The Ark), and soon there were more similar fellowships in the village. In 1969, one opened in Canada and 1970 in India. In Oslo there is Mariahuset, which has a close relationship with the L'Arche movement. Today, there are about 150 L'Arche communities around the world.

Jean says: "My life in L'Arche has taught me that everyone is beautiful. All. Loving people is revealing to them that they are more beautiful than they dare to believe. People say: 'Do you really mean all? How, for example, can you love terrorists?' However, most terrorists have been seriously injured or degraded; they have lived in places where they have been met by disdain. We must pray for them ".

Jean Vanier is a man with a big heart for the small and weak in society, a man who lives as he teaches. He says: "I've been living with these mentally disabled for 45 years now, and they're amazing people. They are fun and they love parties. Every meal can be a party. But you have to be prepared that anyone suddenly can stick the person who sits beside him with a fork, or throw orange peel in the face of the one who sits opposite - but that's life! Many disabled have been so depressed that they do not know they are worthy of love. The day they discover it will be a big jubilee!

Love is not to do big and heroic things. It is to know how to do common things with tenderness. Love is to understand that the one you meet is precious and important. We can only get peace if people begin to meet each other. "

*Anne-Mette Pleijel Johnsson*





Rita and her mum in the group in Uppsala

## 2. The Community

The Community song is Faith and Light's international anthem, one can say. In all countries and in all languages we sing it with similar movements. In this way we become united across national and linguistic boundaries. It is, in all its simplicity, an amazing song, which shows just what Faith and Light are and wants to be, namely a fellowship. A fellowship for all, where everyone is welcome and where we may be ourselves. Nobody needs to understand or play a role. We want YOU to join in our community. Not a religious mask of pride, or someone's psychological superego, or the picture others have of who you are. We are only interested in YOU!

The Community song goes like this:

*It's me, It's me, It's me that build community (3x) It's me that build community.*

*Roll out over the ocean, roll back over the sea.*

*Go into your parts and build community (2x).*

*It's you... it's us...it's God... it's love that build community...*

### **It is I who make the community**

I'm in this community. My background does not matter. I'm there for my own sake, not because of any old merits. If I want to join, I am welcome, and I contribute in my unique way to Faith and Light's fellowship. I do not need to understand myself here. Here I can be myself. Here I am among friends.

To me, membership in Faith and Light means incredibly much. I work as a priest in a Catholic parish in a big city, and I'm expected to perform thereafter. At Faith and Light, I can so to speak, let go of my stomach and be myself. Be Lasse more than "Father Lars". I give my love and joy, and get new energy from the love and joy of others.



### **It's YOU who build the community**

You are always welcome. You're just the one God wants you to be. You are not a failure or someone who should have been different. You are you, and you are so deeply loved by God, and thus by all of us others. With your special gifts and talents, you contribute to the group, and we want you to join the group. It does not matter which church you belong to, what education you have, whether you can read and write or not, who you vote for or what football team you're up to, what you're good at and what you are not so good at. All that is just secondary. The important thing is that you are coming and that you want to be one of us, and that you want to join our fellowship. You are important.

### **It's WE who build the community**

Together we complement each other. We have another song that's about it.

*You are you, and I am I- alike.*

*You are you, and I am I- different.*

*You are you, and I am I- rich.*

*You are you, and I am I- unique.*

Together we enrich each other. The uniqueness of each and every one becomes an invaluable gift to the whole community. We become all small different colored glass pieces in God's great beautiful mosaic, where each of us has its place, where each of us would mean a hole, an empty place, if we disappeared.

I have two good friends in Copenhagen who are in Faith and Light. The twins Amalie and Elisabeth. They are 25 years old, but look for body and length to be 12 or so. However, their intellect is not wrong, and both speak English fluently, when we give up all attempts to believe that Swedes understand Danish and vice versa. It hurts in my heart every time they tell about their brother. He who is "normal". - You are normal! I want to scream in protest. - A bit shorter, but you are absolutely wonderful people, and you are the ones that are slightly different and beautiful, more precious flowers that light up inside the flower shop, among all of us other red roses.

Together we become beautiful. Together we become God's people on the way to heaven. None of us are compensable. We are all members of our fellowship, and we are all important to the whole, all of us members of Faith and Light all over the world. We belong to each other in a band of love that God has given us. It's a great gift, to be both I and VI at the same time. Being a member of God's family.

### **It is GOD who makes the community**

Without God, we would be nothing. Without God, we would not even be there. Without God, our community will be flat. It would be an organization, a union that would work for good things, but it is God who fills our fellowship with love and joy. It is God who, with His Spirit, leads us along the way, showing us how to do and where we will go. It is God who makes all of us light that lights up and warms in a cold world. It is God who is our origin, and it is God who is our goal. It is God who walks in front of us behind us, who surrounds us on all sides

and guides us with his hand. It is God who gives us hope and that makes us never need to be afraid. It is God who gives us peace, trust and fills us with courage and power to walk on God's paths toward our goal, which is God Himself. It is God who is the foundation of our fellowship, a fellowship full of love and joy.

### **It is LOVE that does the community**

It is through God that we have access to the most beautiful gift that exists - love. We get it for free and all we need to do is to receive and grow in it, and give it to each other. Soon we notice that we are nothing more than just members of one and the same organization. We are friends in a community. Sisters and brothers in the family of God. The friendship we have grows into love, an selfless and durable love capable of receiving all the bangs that a community together with completely different personalities will inevitably give us, each one.

We grow in patience and forgiveness with each other, and we begin to genuinely enjoy each other for the sake of others. I like you for your sake. Not because I benefit from you, but because you are you, and then we can make sure we are different. We manage to work in different ways and sometimes there are conflicts. It must go over and then we are friends again, because we belong together in a community filled with love. God's love is the foundation of the fellowship we have in Faith and Light. We become like sponges that suck water so that you can sprinkle that water on others around. We are God's sponges with his special mission, to spread out of our community his love in the world. "We're on a mission from God!" It's not a bad mission either, what we've got; to help God fill the world with light and love, warmth and truth. We thank you, God, for that trust!

### **It's me, it's you, it's us, it's God, it's love that makes the COMMUNITY**

The community - where there is a place for all of us, and where we can be ourselves - it must build us up. From our community, from our meetings and our prayers to each other, we grow and mature. From this community we can build up and gain power. We do not come as isolated islands in short meetings, where we try to get as much as possible from each other. No, we come as puzzles that belong together, we come to a community to give what we have, and to receive what our sisters and brothers in Christ want to give us. And not least, we come together to receive all that God wants to give. God wants to give us everything, and we need to be in a community to even be able to receive such a gift. In our community, we grow both as individuals and as a group. Here we help and support each other, yes, even carry each other when needed. Here we are developing into becoming more and more true followers of Christ. Our community is the ultimate discipleship, and with God we walk in fellowship towards the kingdom of God. We would love to become God's light so that we can guide others to the kingdom of God. Freely we want to give as a gift what we ourselves have received as a gift: God's love in the most abundant measure. Then join our community. You have eternity to win.

*Father Lars Dahlander, Priest in Our Savior's Catholic Assembly in Malmö, and in the group in Lund.*



### 3. Faith and Light - a prophetic movement

The first time Jesus visits Jerusalem he goes to the temple, the house of God. The second time he goes to the sheep pond, which was a gathering place for the weakest, sickest and most displaced people in society. *At the sheep pond in Jerusalem there is a bath with the Hebrew name Betesda. It has five pillars, and in them were a lot of sick, blind lame and listened* (John 5: 2-3).

First God, and then the people who are dirty, unclean to God and most despised in society, gathered in one place. That order Jesus wants to show his disciples, when he chooses to highlight those who have no value in human eyes. He wants their value before God to be recognized by others. *He had no stately exterior that drew our eyes, no appearance that appealed to us. He was despised and abandoned by all, an afflicted man, accustomed to sickness, one whom he turned away from. He was despised, without value in our eyes* (Isaiah 53: 2-3).

Jesus wanted to honor his Father by visiting the temple, which symbolized God's presence and holiness for the people of Israel. Then he would show us that God's new temple is human, saved through the death of his Son and filled with the Holy Ghost.

Jean Vanier has been called upon to continue this work - showing us the people who are the weakest, the most vulnerable and in the most need of support. Jean has devoted his life to saying that every human being is beautiful and has a beauty that reflects the beauty of God. That every human being has something to give to others if we are patient and want to open ourselves to it.

Jean has many times said that if we want to see God, let's look down, not up! He has continued what Jesus began to do - turning our image of people up and down.

During my years in Faith and Light, I have seen how this has affected me and others. Jean's gift to show each person's unique value has characterized me. In a society that honors status, wealth, power, success and beauty, it has helped me to experience the truth in Jesus' words and actions. My contacts with the members of Faith and Light have shown me that this movement is prophetic. A prophet is someone who has "knowledge of salvation," as we read in Zacharias words about his son, John the Baptist.

Faith and Light Movement is prophetic in the way that it attracts attention and forces us to reflect on what we experience in its members. It points to a way to experience how Jesus turns human values up and down. Just as with other prophets and prophetic movements, it has taken time, patience and endurance for its message to reach out. Being established in so many countries is proof that people listen, learn and live as they teach the weakest in our society.

There is an idea that the strong in society would serve the weak, and that is true. But what the strong finds if they take their duties seriously is that they themselves are served by the weak ones. Those people who have "visible" disabilities make them a strong service by forcing them to take a stand and discover what is in their own heart. They realize that they themselves are weak. The weak ones often show an inner harmony that the strong lacks. They teach us patience, endurance, gratitude, and having a humble attitude to life. The weak ones show us our weaknesses and limitations. They challenge us to look clever on ourselves, and realize that we actually all have our disabilities.

In our country, handicapped people have many benefits that are not found in other countries; a social service that helps with housing, travel services and interpreters. But basically it's fellow human beings. The human contact, empathy, warmth and patience to learn to interact with each other can not be replaced by social services. There are so many parents who show heroic devotion to their weak children, and so many friends who always are ready to help, and it raises awareness of how good people can be. They have responded to a call from God to love their neighbor. They have done and do boundless.

In one of his letters Jean Vanier thanked God for L'Arche and Faith and Light. There he writes that the world is calling for places where all people are welcome. He means that each of us must continue believing we can do something to break the indifference, the fear and the evil that exists in our world. We will keep our hearts open and loving and be close to those who need help. We will work to create communities based on God's love, and be open to those who experience isolation and rejection. I often wonder why it took almost 2000 years for L'Arche and Faith and Light to be born!

All those involved in these movements are on a journey. The road is open to us to continue living according to these words from Paul. *Keep in mind when you were called: not many were show in the worldly sense, not many were powerful, not many people. But what is foolish for the world, God chose to show them shame, and what is weak in the world chose God to make it strong with shame, and what the world is looking at, what is being called, Yes, which is not available, God chose to end what exists so that no person could be proud of God* (1 Cor. 26-29).

*Father John McCormack, priest in the group in Stockholm*





#### **4. I'm not here as a volunteer, I'm here as Heidi!**

Fifteen years ago I was invited to a lucia celebration. As I came there I ended up in the lucia train, I who could not sing. The question they asked when I came was not, have you arranged lucia clothes? Can you hold a ton? Have you learned the texts? They simply asked if I wanted to join and I wanted to.

Now I'm sitting here many years later with the question of what Faith and Light means to me.

When I'm in charge of something, I tend to sit up at night and plan and practice for everything to be perfect. I am nervous and worried that what I'm going to do will not be good enough. When you do something with Faith and Light, everything can happen, and it rarely ends as you think. This does not mean, of course, that I can ignore the preparations, but I can prepare a little bit. How could I know that the great mime with the entire group that I prepared, would end up with someone finding a crayfish in a boat and then everything was about crayfish! I have learned to do my part and then take the group towards it and do something about it. I can rest that even if someone prepares, we'll do it all together. I dare let

go of my control, it must not be perfect to be welcomed and embraced.

It's about daring to come with my weakness, my nervousness and fear, to really understand that I'm welcome as I am, that it's alright if I want to be quiet in a corner or if I want to take a lot of space. Instead of preaching everyone's equal value, you have to live it. I realize that it also applies to me. I have a value in myself.

My value in Faith and Light is not in how good I am, how well I plan things and how fun I can be. It is just there, my value. And it's not a matter of being popular in Faith and Light. Some still do not greet me when we meet, but just look skeptically at me. But we have both chosen to come here, meet an afternoon every month and go to camp together. Despite our differences, we are important to each other, even those who do not talk to each other. We share something.

To me, as a high-performance, "good girl", Faith and Light does not mean that "he in a wheelchair" is welcome as he is and has the same value as everyone else (of course he is, and of course he has), but I am welcomed as I am, and no matter what I perform, I am valuable. I do not come as a volunteer to help and support others, I come as Heidi, and experience how it is to be welcome and valuable just as I am.

*Heidi Jonasson*





## 5. Behold, the Lamb of God!

It's the third time I travel to Trosly in France, to the village where Jean Vanier in 1964 bought a cottage and moved in with two mentally disabled men. Now there are many similar communities there in the village. The whole village is characterized by L'Arche. Workplaces have been created, including workshops, studios and gardens, where disabled people have a paid work.

We will be staying at La Ferme for a week, together with other participants from Scandinavia, joining a retreat led by Jean Vanier. La Ferme is a farm converted into a place of silence, reflection and prayer. Here you have time to stop, think and reflect. It is balm for the soul.

We walk around in the little village, whispering to each other to not disturb the silence of the others, and we eat our meals in silence with music in the background. In the chapel, we start and end the day in prayer and silence. God's presence is evident.

Then it's time for reflection with Jean. We sit quietly in *Pianissimo*, we pray and sing some Taizé songs. Then Jean comes in, silent and unnoticed. He waits in the back of the room, wearing the same blue jacket that he always wears. As we finish singing, he goes forward and sits down, placing the Bible on a table in front of him, but rarely opens it during the hour we have together. When he talks, we understand that this is a book that he has lived

with for many years. It is one with him and as he talks about the gospel of John, one chapter at a time, one senses his love for this book.

He talks about how John the Baptist saw Jesus. "Behold, the lamb of God!" he says. The first name Jesus receives in John's gospel is the Lamb. The people waited for a Liberator. They wanted the Lion of Judah, but the one who came was the Lamb who removes the sins of the world. God makes himself weak and vulnerable, like a fierce and defenseless lamb. But the power is perfected in weakness, and in weakness we discover God. God is in the weak. There the walls break down and we enter into a fellowship. The weak leads us into fellowship with the Father.

### **The sacrament of love**

Why are some people born disabled? Is it a punishment? No, says Jean, they are a sacrament - they are holy and God Himself works in and through them. They teach us the way to God and they teach us tenderness. They teach us to look at people without condemnation, and to listen to what is said behind the words. They teach us a way of living, believing in people, seeing them.

Jesus wants to help us look behind the exterior, looking at each person with tenderness. See that in every human being there is a child who is vulnerable and in need of being loved and gaining tenderness.

The weak are the sacrament of love that can transform us. They help us understand that every human being is precious, but also that I am a little child who needs tenderness and need to learn to accept myself. We do not need to protect or defend ourselves against each other. Our task is to create a relationship. There, in the relationship, there is also God.

There is much fear in us that we need to be freed from, but tenderness is healing, and in the relationship with the small and weak we can be freed from fear. We can give something to each other. It's not just me who'll give you something. We give to each other.

### **The woman at Sykar's well**

When we find it hard we call for God. We long for a relationship. In John chapter 4 we read about how Jesus calls for a relationship with the Samaritan woman. "Give me something to drink!" He meets a person whom others look down on. A person with broken self-esteem. But Jesus does not judge, He accepts her. He shows her weakness to her. He is tired and thirsty and he needs her. "Give me something to drink!"

The deepest thirst of man is to get a relationship. Getting friends who accept, love and forgive. In each of us there is the question "Am I loved? Is there anyone who cares about me?" Jesus thirsts for a relationship with me. He longs for a meeting and he offers a change. - Give me your water, and I'll give you the living water. *The water I give becomes a source in him with water flowing to eternal life* (John 4:14). When I drink of the water that Jesus gives, I can also pass it on. As I drink from the source, I become a source that can give the water of life, the water of love, to others.

### **Lazarus - a special friend**

Jean tells about Jesus and Lazarus: Jesus is in Jerusalem. He walks around in Solomon's pillar hall in the temple, talks with the Jews and teaches about his Father in heaven. He says, "I and the Father are one!" How can he say that? He's blaspheming! The Jews want to stone Jesus, but he goes away from them to the place on the other side of the Jordan where he was previously baptized by John.

Then he receives an urgent command: "Lord, the one whom you love is ill!" Jesus immediately understands that it is his friend Lazarus. A very special friend. One who is particularly dear to him.

Lazarus lives in Bethany, a few kilometers from Jerusalem, along with his sisters, Martha and Mary. Jesus often stays with them when he is in the neighborhood. Maybe Lazarus was disabled? We do not know. But we know that it's Martha's house. It is she who has the main responsibility, not Lazarus. And we know that she and her sister have chosen to live unmarried, perhaps to take care of their brother?

Lazarus is deeply loved by his sisters, and he also has a special relationship with Jesus. When his sisters send a message to Jesus, they call the brother: "The one whom you love". And Jesus speaks of him as "our friend Lazarus." This is Lazarus's identity. He is the friend of Jesus, special, beloved and precious. It's also yours and mine identity. Also we may be Jesus' friends, and be loved by God. And in that relationship, in meeting with Jesus, we find the meaning of our lives.

This is one of the most beautiful stories in the gospel of John, says Jean. It shows how deeply human and at the same time completely divine Jesus is. It is about how Jesus loves the people and awakens from death a man who has been in the grave for four days, whose body has already begun to break down. It is about Lazarus who was ill, in Greek *asthenes*. The word *asthenes* can be translated ill, without force, weak or insignificant. Today, we would probably say that he was handicapped.

Jesus is deeply affected by Lazarus's death. He gets terribly upset when he sees how Mary and the others mourn, and he also begins to cry. Jesus enters the pain and he shares the sorrow. Those who see Jesus say, "See how he loved him!"

"Come out Lazarus!" cries Jesus, and Lazarus comes. He who has been dead for four days is liberated and raised. God wants to deliver you and me from what is dead and dark in us, just as He liberates Lazarus. He calls: Come out! I want to give you a new life. I want to give you my life. I have come for you to have life, and abundant life.

### **God has chosen the weak**

For my part, the contact with Faith and Light and Jean Vanier's teaching has meant a lot. It has taught me that every person is unique and valuable, regardless of any disability, and that in every person there is a small vulnerable child who longs to be loved. Whether it's a person who is small and weak, or one who is big and cocky, it's my job to look behind the outside and love that person. But in my own capacity I can not love every person I meet. I am totally dependent on God.

I have had the privilege of getting to know Klara, who is severely disabled and needs help

with everything. She is totally in the hands of others to meet her basic needs. One might think that a person with so many difficulties and disabilities never can have a good life. Does her life have any value? Yes, Klara has a good life, and her life definitely has a value. She has a family who loves her. She has amazing assistants who make every effort to help her develop and to get what she needs. Klara, like every human being, has a value because she is created by God, and is precious and valuable in his eyes. Klara has taught me that as she is totally dependent on people around her to get what she needs, so I am totally dependent on God to be able to live as He wants. I trust that God gives me the love I need to give to my fellow human beings, and that he gives me strength in difficult situations.

Thanks to Klara, I have also realized the value of trying to live more in the present. For her, it is obvious, it is here and now that applies. I understand that my attempt to perform something and be good has very little significance. It's more important to be than to do. Jesus says that the Kingdom of Heaven belongs to those who are poor in spirit (Matt.5: 3), those who have nothing to bring, those who do not show up their merits and talk about how proficient they are. Therefore, I can put down all that I have and stretch my hands toward God and say, "Now you have to take over. I'm totally dependent on you! "

Life is sometimes not so simple. Relationships with people around me can creak. I face trials that make me sad and afraid. Just as Klara sometimes shows her frustration when she does not understand what is happening around her, or when she can not express her feelings in any other way, I also may show my anger and frustration. I do not need to disguise and try to show a nice facade. I know God understands, and that He loves me and wants to help me through the difficulties. Whatever happens, I am in His hands.

Klara can not see or talk, but still she has a lot to give. When I see her happy smile where she sits there humming to herself, or when she stretches out her arm to give me a hug, it feels like I have received a precious gift. That gift warms more than anything else, because she gives something of herself and I can only receive.

God has chosen the weak, the foolish, the insignificant and despised that the wise and strong may be ashamed (1 Cor.1: 27-29). In the mentally disabled there is often a great openness for God. There is a holiness in them that helps them in a special way find the closeness to God.

Jean Vanier says: "Does the Church really believe that people with disabilities are holy? Some believe that the Church should do good deeds for the poor. But do we think they are holy? I'm enraged when people say, 'You're doing a good work.' I'm not interested in doing a good job. I am interested in the Church's vision of fellowship, and of living with the disabled in a community based on the gospel. We are siblings together, and Jesus calls us away from society's power pyramid to become one body."

Jesus came to our world to help us find a personal relationship with our Heavenly Father, and to teach us to love each other with the Father's love. We are called to make the world a place where this love can prevail.

*Anne-Mette Pleijel Johnsson*



## Part 2

### Experiences from Faith and Light



Berit Keszei and Jean Vanier

### 6. Forty Years with Faith and Light

My life in Faith and Light has been long, almost for 40 years. It has been very rewarding, instructive, loving and it has taught me to understand that the most important thing in life is love. Love to God and to my fellow human beings. It has helped me in many difficult situations to realize that all people need love and acceptance, to understand and hear the cries of fellow men for help; understand me, enjoy me! If I had not the opportunity to meet Jean Vanier and my friends in Faith and Light, I think I would have been a completely different person with totally different values. Faith and Light has given me so incredibly much!

#### **Worship**

The Faith and Light group from Gothenburg was many years ago at camps in Lövekulle. One evening we had the worship of the sacred sacrament in the chapel on the spot. As you may know, you are quiet and pray in silence before the body of Jesus. The group sat there quietly and prayed. The lights were lit on the altar and it was quiet in the otherwise dark

church hall.

Then Michael and his mother entered the chapel, a little late. When Michael sitting in his wheelchair reached the altar he cried out loud with joy. I have never heard him so happy before. He knew that God was there. He felt God's presence! This is a memory I hide in my heart. I know that Michael, although he can not express himself in words, is much closer to God than I, despite all my studies and trying to understand.

### **Sackeus**

In Faith and Light we often mimic stories from the Bible. In a camp we should mimic the story of Sackeus. Harry, a grown-up guy, had the role of Sackeus. He climbed bravely up in the tree on the plot, and there he saw very well when Jesus came walking and called him down. But there was a stop. Our Sackeus did not dare to climb down. How we tried, tugged and prayed, he did not dare. In the end, we have to ask a neighbor for help and he brought a ladder. We needed help from more neighbors. After much wheedle we finally got Sackeus down from the tree. I can assure that none of us ever forget the story of Sackeus!

### **Career Steps**

At an international meeting in Santa Domingo, Jean Vanier talked about climbing the career ladder and how alone it was at the top of the ladder. No support from others, maybe no understanding, only loneliness.

I remember that I cried and cried. I had just finished my studies, and were on my way up for those steps, just to know that it was not the purpose of life. It was down there, below the steps that I should be. That was where my help was needed. That was where I was needed. Oh, so grateful I am for that lesson today!

### **Blessing**

At the meeting in Rome, I was also blessed by Franco. It was such an indescribably wonderful feeling to be blessed by a disabled person. To be comforted by him was so salient and healing. We had been in Rome, and I had been robbed on my wallet with a lot of money, but Franco comforted me with his blessing.

### **Governor's Palace**

At an international meeting of Faith and Light leaders in Quebec, Canada, we were invited to the governor's palace, where Jean Vanier's parents lived when his father was governor. Outside the castle were guards with nice fur caps that were admired a lot by the participants. Once inside the castle we were invited to drinks and snacks. The music played in the meantime as we mingled and talked with the governor and staff. Some handicapped participants thought they would live up the music, and therefore began to direct it in the way they liked it. After a while, there was spontaneous dance, and the handicapped, of course, tried to engage the little rigid and withdrawn governor. His secretary whispered to me: "Something such has never happened before in this house."

Imagine what a little spontaneous joy of life can do!



**Thank you for Faith and Light!**

There are so many memories from all these years in Faith and Light. It has meant real friends and love. It has meant traveling across major parts of the world, to places that I would never have otherwise visited. It has meant meetings with like-minded people, who today are my friends and I have contact with. It's so amazing that wherever you are in the world in Faith and Light, you feel at home. It is the same understanding, the same love and consideration, almost the same programs, the same pleasures and difficulties. It is a place where we understand each other well, and were we really support and care about each other. And everywhere God is included as our true support.

With all my heart, I thank God for Faith and Light!

*Berit Keszei*

I like when we play and sing and dance. Particularly singing with movements. I always think it's fun to be here.

*Bernis Adolfson*

Birgitta passed away recently. She really loved Faith and Light, and she never missed a meeting. She especially liked the camps. She liked that the program was about the same from year to year. Particularly Faith and Light Olympic Games she liked, and the music and the songs and when we danced with flags. Everyone was so kind and helpful, and in the kitchen they made nice food for her. She really loved being at the camp in Vadstena.

*Birgitta's assistant*

I was here with Claes and he loved Faith and Light. Here they listened to him. He was able to read his poems for us. He liked that.

I like Faith and Light for here I can join in.

*Margareta Sommar*

It's so nice to be a clergyman in Faith and Light. You can be yourself, remove the mask and just be. One feels that you are among friends, that you are well-liked, accepted and loved as you really are. It is wonderful that everyone can join in and be seen.

I often wonder why it is so hard to interest other priests for Faith and Light. They would also need to share the Faith and Light healing effect.

*Håkan Jerrhage, Priest in the Gothenburg Group*

The best thing about Faith and Light is that everyone can fit. Whatever we are, everyone is welcome.

*Andreas Lindholm*

I like Faith and Light because you get new friends and everyone can join. The best of all is the camp in Vadstena and that you meet and can be together with all friends.

*Hanna Tynnemark*

I think it's good to meet each other, it's fun to hang out.

*Daniel Ensgård*



## 7. Mariahuset

*At the bottom of the social steps  
He joins all those who have been rejected,  
and with them He creates a new order, a new community.  
They are the starting point of this new creation,  
this new humanity.*  
(from the book *Befriending the stranger*, by Jean Vanier)

We sit around the table and eat. Laila looks closely at Synnøve, who eats with her head lifted and with good appetite. Synnøve is blind, and it is not often she lifts her head or has any food cravings. But she notices the warmth from Laila, and is really involved in the community around the table. Susanne notices Laila's calm and presence, and laughs quietly. Erika sees what happens, and one after another can see it. In the end, we can only burst in laughter over this indescribable thing that happens between us, there in the kitchen.

Most of us sitting around the table have lived together for almost 40 years. Our community is called Mariahuset and started in 1975. We have our roots in the L'Arche movement, which we also have close contact with. L'Arche, or The Ark, started in 1964, when the philosopher and theologian Jean Vanier moved in with Philippe and Raphael, two men with mental development disorder. From this small house in the village of Trosly north of Paris,

The L'Arche movement has since expanded with housing communities on most continents. The idea is to live together in mutual fellowship, where the most vulnerable should not be wasted, but to have a central place in the community. The idea is also that the whole human being, with its various cultural and religious stories, will be welcome in the

community.

Mariahuset is a small ecumenical community. We are Lutherans and Catholics, or have any other religious horizons. Three of us have diagnoses from healthcare and came from different institutions as ten-year-olds. Together we represent a wide variety of differences. But one particular difference is that some people sat or lay in institutions and waited, while others could choose to come to Mariahuset. Life in community has really been born between us.

We live together with all that it means of challenges and pleasures. It's an every-day community. We pray and work together, cry and laugh, dance and sing, weave and fabricate new paper of old paper. It's days and nights, both in concrete and transmitted meaning. Some of us who belong to the community live outside Mariahuset, but have their working day in the house. Others come and share the community at the weekly show in the chapel of the house. The whole is a network of friendship where diversity and ceilings are great.

We who make up the community all came with the different stories we are characterized by, good and bad. Some of us had experienced getting lost, trying to protect themselves by disregarding others or being destructive. Others expressed their sorrow by refusing to eat. When I met this exhausting expression of internal pain, an intense work started in me. The head worked with educational solutions; a safe and clear day rhythm, meaningful moments and work. Everything that could bring life and joy. When my body encountered strokes, memories of earlier blows and conflicts were awakened. The scream met my own scream. My look became hard. The hands that had to keep became hard. Who was I?

I had an experience of having a gap between head and body. The body was a doer. It was easy for me to work practically, to be a helper. When the solutions were not in the words, there was a fear of being dissolved. It could easily lead to dysfunction in the body, or to paralysis. Starting from the head to the body was like getting through a deep tunnel.

Then we met again, we who had been hit and held with hard hands. We met openly. "You're here again!" I got a friendly pat where I had a blow. The difficult feelings had to be removed as well. Often, over and over again. And if it was impossible to ask forgiveness with words - what does the words mean? - yet the forgiveness felt like a living reality between us. As if there was something underneath us who was carrying.

Who is normal or abnormal in this?

Common to all of us was the longing to be received as we are, to be loved. The destructive expression is often a cry for unconditional love. We were really fragile people in the same boat. But something began to happen. We were and we are a community, and we are several who can carry and who can talk to each other, and that is a great help.

Then we live as fellow wanderer, handed out to each other. And I suspect Susanne, Synnøve and Laila are helping to release some of the deepest in us. In concrete constraints, they can trigger the hope in a way that only those in their vulnerability can do.

We are in the same boat, and above us there is a high sky.

*Bodil Sødal*



## **8. The trip to Mariahuset, and the wordless comfort.**

It was spring that year when we made the trip to the Mariahuset in Oslo together. We were eight people in the minibus. Of the children, there was only room for Johannes. I was sorry that our daughter Sarah did not get that opportunity. I would like to show her that there are many different ways to live. Perhaps this visit could have inspired her in the future, and become part of her life.

Sometimes it's more difficult to get over one's sadness. It may open up an old wound that is hidden far down in the darkness of one's soul. Something you do not want to remember, do not want to know. Sometimes it seems that God is very keen to want to use those opportunities to get our attention. God knows that what hurts is lying there and hiding, and he knows how much energy it takes to be afraid of it. To put the lid on and still be afraid that it will come to the surface and mess up. God knows how chased we can be from what hurts. How we try to escape and make us fully occupied so we do not have time to look after. God is suffering with us and wants to help us so that we can come to rest. For real. So that we can enjoy the beautiful life he wants to give us and that we are living.

I remember that I thought the trip to Oslo took forever. I remember the feeling of great abandonment. Being invisible. I could not get out of the sadness, and the isolated bubble I was stuck in. I was as frozen in myself. Could not ask for help. Though we all sat so close to each other in the minibus for many hours, nobody noticed how I was feeling.

We arrived. What a beautiful house! So beautiful everything was indoors. They had been waiting for us. We stood in the kitchen. Bodil was busy preparing the rice porridge, and the others in the family sat around the dining table and looked at us. "Welcome!" Perhaps we sang a song. I remember we were standing there, and the horrible bubble I could not get out



of was still there. Then one of the women gets up from the table. Goes straight to me and takes my hand and takes me to a place at the dining table next to her. She does not let go of my hand. Not during the whole meal. We eat with just one hand. Both of us. It makes me smile. She does not say a word. We are absolutely quiet both of us. But something happens to me. I feel that I have a heart and that it's getting warm. The bubble, the ice cold, melts. I'm so incredibly relieved. So grateful. She knows what's happening. She feels my relief and warmth and lets go of my hand. I'm astonished that she recognized me immediately, that she saw me and knew, and that she had the ability, responsiveness, sensitivity. She understood what needed to be done. Certainly and lovingly. She, Susanne, is one of the disabled women who live here in Bodil's family. They are a family, not by birth, but of the Spirit.

That night I danced for a long time with one of the other disabled in the family. We were so present with each other, in such peace and rest, where we slowly touched, holding each other's hands. Time disappeared. I enjoyed, full of gratitude about being there. What a gift!

The next day was a Sunday. The family would go to church. What church they go to they decide in the morning. Today, the choice fell on the Catholic Church. A little anxious I was maybe, or disappointed. It was supposed to be communion, and then, as I am not a Catholic, I could not receive Jesus in the bread and wine. That had been such pain to me every time, when I was among Catholics. So, as it was a pain to be left out, and "not worthy" in so many contexts of my life before, even before I became a Christian. The pain in this wound of exclusion did not get any easier now that I was a Christian. On the contrary. So the trouble was there, though I tried to accept the state of things as much as I could.

Then Susanne comes to me again. Certainly she takes my hand and takes me to a place where she wants us to sit. She does not release my hand. She says nothing. Now I know she never says anything. That she is speechless. But that does not stop the intensive, intuitive communication and presence that exists between us. She's really here with me. And I with her. She is intensely present in liturgy. She draws me into it. I am so extremely concerned. And when the congregation sings "Kyrie Eleison, Lord, have mercy on me," we both start to cry. The tears running down our cheeks contain all Susan's wordless pain, which I can share just now, as she shared my pain yesterday. And I feel that she is closer to Jesus' heart in her vastness and nudity than many of us in this sacred place. It is truly a holy moment, a holy meeting, which I experience there and then. Later, when it's time to receive communion, I was hoping to avoid it, as I am not allowed to receive. But Susanne had other thoughts. Certainly she pulled me to the altar, and I was blessed by the priest. Susanne was happy. Then we had to travel home.

I had experienced something that I have never forgotten after all these years. How God is present in the little ones. Those who are nothing in the eyes of the world. Those who, in their pain, open themselves wide open to God, to live, survive. Those who let themselves turn into bread and wine for others. Those who let us meet God, where he allows himself to be. Thank you Susanne! Thank you Mariahuset! Thank God!

*Anneli Lendrup*





Johannes in his workshop, *Wood and Light*

## **9. We have a little prophet in our family**

So we usually say when someone is wondering how it is to live with a handicapped child.

Almost eleven years ago, Johannes was born, the first boy after three girls. We had said our "yes" to this child even before birth. We had said no to amniocentesis, with the knowledge that the older mother there was the greater possibility that the child may have, for example, Down's syndrome. The child was welcome as God allowed it, a gift.

He came to the world a little dramatically, at home. Once he got to the hospital, he was examined for a long time. Then we understood that it was "something". And then the words

came: "Your child probably has Down's syndrome." At that moment everything became still, as if God would give us time to open our hearts to receive His gift. And we did. But it is also painful to have a disabled child. In the evening, cry, worry and questions came. What are we waiting for? Will we do this? What consequences will this have?

But we were comforted and encouraged in different ways. Godmother sent the well-known image of a child sleeping in a hand, with words from Isaiah: "You are mine." "I, the Lord, is the one who called you by name." "For I am the Lord, He who has created you. He who made you already in the womb and helps you. "

And we remembered that God had wanted to prepare us, as we waited for Johannes. We watched a children's program on TV with the girls. It was everyday pictures from a 3-year-old boy's life. He was called Joel and had Down's syndrome. We laughed because everything was so fun with him. And we said, "That's how it may be when you have a sibling like the little TV guy." This is what they remember when it became "real".

One week after birth, it was confirmed that Johannes had a severe heart failure. Operation with quite high mortality rates would be necessary within six months.

It was as though God wanted our first "yes" to widen into a bigger "yes". Yes, we would love this child also in the pain of knowing that the next moment may not come, seeing him become weaker. Moment for moment, we lived for Johannes, that was the only way possible. Only two words were relevant: "Food and love." Gavage, vomiting, eye contact, gavage, vomiting, eye contact, gavage... After five years we still found stains from his food on the ceiling and on the walls. The girls were gathered around Johannes to caress, kiss, talk with, carry. And in all pain and fatigue we were happy, everyone.

Sometimes we heard someone horror-struck that we spoke openly with the girls that Johannes might only live for a short time. They were so small. But just the transparency made them safe and they were experts in living the present in love with Johannes.

In the end, Johannes became so weak that the planned operation had to be made earlier. Then a telegram came from a good friend: "We pray that God's LOVE PLAN will be fulfilled." This wonderful word LOVE PLAN carried us through everything. A plan of love for each of us. In light of this, it was not crucial whether Johannes would have a long or short life. We just wanted to thank God for everything, knowing that He loves us all endlessly.

During the operation we celebrated the eucharist in a small room at the patient hotel. The window was opposite the big windows of the operating room. Then we handed everything over to God.

And the eucharist carried us through this moment. The word of entry was: "I hope for the Lord, I will rejoice in your grace." But we also received the sacrifice of prayer: "Lord, let our life be one with this sacrifice so that we crucify our old man and rise to the new life of Jesus Christ our Lord. " And from Isaiah's book, we read "I want to create new heavens and a new earth ... there shall no more be children who live for a few days." And the gospel was about the captain who asks Jesus for help: "Lord, come before my child dies". Jesus answers: "Go home, your son lives." Your son lives! We knew it was true whether Johannes would live or die.

For a month, Johannes was anesthetized in the intensive care unit. Throughout this time we

had the opportunity to celebrate the eucharist every day. We were carried by the Eucharist, the daily texts and all the prayers. For example, when trying to quit the sternum a few days after the surgery and opened it again, we read in the collective prayer: "Give us, Lord, the good spirit of endurance." And "Happy is the heart you seek for the Lord. Ask for the Lord and his power, seek his face constantly." All words became alive.

Half way everything seemed good and we allowed ourselves to hope a little bit, because in the next moment we were facing the big uncertainty. Pneumonia, blood poisoning, the sacrament of the sick, pick up the girls by airplane, just in case...

This happened on Palm Sunday, and Christ asked us, "Are you also following me this last piece of the way?" We lived the Passover with Christ and all His Church. On Easter eve everything turned, the fever went down, he began to breathe himself and on Easter day Johannes was taken out of the respirator.

Now we have lived ten years with John. Our outer lives are limited in many ways. We can not visit friends or do activities that we would "like". We still can not go to children's theater or anything else for children. All "new" is an additional threshold. Johannes has many fears and you never know how he will react. He does not speak much, can ask for help when he wants something special, for example listening to a certain band or being hungry. Sometimes it's hard to understand his reactions that often depend on his autistic features. It often creates frustration and disappointment, but we have learned that if we just love without thoughts, the solutions will come to us.

Today we can testify about what gift he is for us all, every day. He reminds us of what is essential in life. He is the one who lives in the present, completely satisfied. He is true. He never shouts back. He is never calculating. He does not understand irony. He never defends himself. He is open to receiving us every single moment. He is also a barometer of how the climate is between us in the family. If we quarrel and argue, then John cries. That NONE OF US wants, it breaks our hearts. Then he helps us to immediately reconcile and correct what went wrong.

He invites us in a special way to love him and each other. He is the one who teaches us by "just being".

He is the strong one, we are the weak.

We agree with what Pastor Tomas Sjödin and his family wrote when one of their sons, who were handicapped, died:

We carried you all your life  
But you lifted us

We have received a gift, we just did not know it was so big.

*The Karlsson family*

PS. Johannes is today, 2018, 27 years old and happy with his life.



## 10. Klara

**Anne-Mette:** Tell me what happened when Klara was born.

**Eva Svensson:** It was in the summer. Klara was born a little too early. The birth went well, but I got a fever and went through various examinations, which meant I could not have Klara with me at the beginning. It was found that I had a B-streptococci that needed to be treated with penicillin. Klara, on the other hand, was good and ate well and seemed fully healthy. But even though she ate so much, she did not gain weight, which I thought was a little strange. Five days later it was clear that Klara had the same streptococci as me, and because of this, she was in a very severe meningitis.

It was a miracle that Klara survived, and after one and a half months at the hospital she had recovered so well that we could go home. We realized she had been injured, but thought that "a small disability, does not matter". When we then got the answer to all samples it turned out that she had a very severe brain injury.

Klara was born into our family, consisting of me and my husband Håkan, as well as the



brothers Joseph 13, and Jonas 10 years. From the beginning there was a lot of effort from habilitation, and our home became a federal center. There were more and more contacts with various establishments concerning her health, her body and her opportunities for development. We have had to struggle a lot and coordinate and have had many own ideas.

Klara loves music, and she has a lot of power in herself, but her injury means that she is blind, has no speech, has limited mobility, a very tense body and a severe developmental disorder. In recent years she has been living in her own house, with personal assistance, and thanks to this we feel that Klara has a good quality of life. She is often happy, and also spreads a lot of joy and love through her hugs. No person close to Klara can remain unaffected.

**AM:** How has this affected your faith in God?

**Eva:** When Klara was a newborn, I received a lot of comfort from Psalm 121, which I received before she got sick: *I lifted my eyes up to the mountains, where should my help come from? My help comes from the Lord who made heaven and earth ... The Lord is your protection on your right ... The Lord will keep you from all evil.* But I've also struggled much with those words. They have comforted me and they have made me despair. What do you mean, God, by preserving Klara from all evil and that you are her protection?

During Klaras first time, we had contact with a family who, together with us, formed a small group around Klara, whom we met at home to pray for her. It was a big support for me and meant incredibly much.

During a retreat, I once saw a painting that caught totally. It showed a little girl with red cape walking with her mother. In that picture I saw Klara. I was talking to one of the leaders of the retreat and told about my experience of the painting, and about my sadness and concern for Klara. I then got the wise advice to go to counseling, as it is important to process the experience, and to put into words what is difficult in the situation, in order to be able to accept it.

I have therefore searched for different places and people, and thus received support and assistance for processing. I had so many questions; Is there an meaning with everything that happens? If God really is Love, why did he allow Klara to be born healthy, then to be so badly injured? Can she be healed?

The questions have no answers, but have been important for me to ask, and eventually I have found rest in God's Love. He does not want everything that happens, but as almighty God he transforms what seems meaningless. My calling is to relate to what I meet, to get help from his love, and to let God be the one who carries and helps.

In any case, life itself is a wonderful gift. God is love and He loves us and wants to carry us through the difficulties of life. He has promised to be with us all days, and with his promises we are given the opportunity not to get stuck in self-esteem or bitterness. The narrow road seems to be rest, trust, surrender and hold on to the promise that for those who love God, everything works for the best.

When you wait and wait for the prayer answers that you so earnestly hope for, it seems to do something with one's view of God. Something happens on a deeper level. I am so grateful

that God has helped me to keep my faith in Him. Whether there are still hard bits of uncertainty and anxiety for the future, I want to try to put everything into God's hands and practice trust in Him. He has promised to be my support and I know that he hears prayer, although sometimes he is silent and does not answer as I hoped. But I can trust that he hears and that he shares the pain. I also really see a lot of answer to prayers and proof of God's great care when I look in the rearview mirror.

I increasingly see God's infinitely big gift in Klara. Klara is completely unaffected in her soul and spirit and she is absolutely true. Together with her there is always the opportunity of wonder, gratitude and self-knowledge.

**AM:** What has Jean Vanier and Faith and Light meant to you?

**Eva:** We participated in a retreat with Jean Vanier in Floda, organized by the community in Mariahuset from Oslo. There I saw what incredible respect Mariahuset showed their disabled friends. It was amazing! Jean Vanier's teaching and his books have also given me a lot. His message is really so simple. Before, I had sought a lot of healing in different contexts and hoped for God's intervention. But what Jean communicates deals more about healing on a deeper level. It is about an inner healing and an assurance that God is love, and that he identifies himself with the weak and vulnerable. God divides our living conditions and carries despite despair and impotence. When I set the conditions, disappointment is behind the door, but when I accept it as it is and put it into God's hands, it opens up for God's presence and opportunities.

I am infinitely grateful for the joy and community that Faith and Light give. At the same time, it's a pain that it has not been easy for Klara to participate. Some parts are hard for her, but when we are still in the prayer time, and when we are singing taizé songs, she is usually very quiet and contented. And at our summer camps when we celebrate the communion, she is so marvelously involved and present. Klara is also completely overjoyed when we have disco and when the marimba orchestra plays!

A dream I had for a long time is that Klara would come to a Mariahus or a L'Arche community where she would live daily in a spiritual fellowship. It would be so wonderful for her.





## 11. Wilgot

**Anne-Mette:** Tell me about Wilgot and what it's like to be mom to him.

**Hanna Rudebrant:** Wilgot has Down's syndrome, severe developmental disorder and autism. When we got him, I felt that I was a little special, who had such a child. I thought this would be a different trip. But my relatives and my friends, on the other hand, had difficulty accepting and understanding how they would behave.

During his first year, Wilgot did not gain weight. He had a wound on the cardia that caused him to vomit all the time, and it was quite awkward. When he grew older, we felt that he was different. It was completely impossible to teach him to eat during the first two years. The only thing we could give him was gruel. I remember seeing another child of the same age, with Down's syndrome, who was eating with a spoon, and I almost fainted! It was completely unthinkable that Wilgot would do it.

When he became two years old, he began to eat, but all he could have for a whole year was a baby food casserole with turkey food. I went to the store and bought a lot of turkey food, but as soon as he ate something else he was vomiting. Eventually, he went well and now he is very fond of food.

Being a mother to Wilgot is a challenge in many ways. I am the one who is closest to him, who understands him best and who has the main responsibility for communicating with him. I also have to be the spider in the network when it comes to all healthcare contacts and school contacts and all that. It feels like a whole stream of phone contacts and visits to different

places that never end.

But it is also exciting with Wilgot, because we in the family get a completely different perspective on the life that we could never get if we did not have him. Just this to be together, to be close and that it is not so important what you do or what you say, but just be together. When Wilgot was small for example, and we went out with him, he was incredibly fascinated by how it blew in the trees. He could sit for a long time and just watch how it blew.

We often come close to each other and get that nice "heart contact". When Wilgot and I are alone, he often begins to sing on the Community song, which we usually sing in Faith and Light. "It's me, it's you that build community..." I would like to say that there is some kind of God dimension, an eternal dimension that comes into existence. Jesus says that we should not despise the little ones, because their angels in heaven always see their Father's face. I often experience that with Wilgot, that we always have God among us.

Wilgot never plays any roles. He shows very clearly what he needs, and we must meet him no matter how hard it is. That is also how God does with us. He bends down to us to help us no matter what it costs him. Wilgot becomes such a strong reminder of it.

**AM:** Has the situation with Wilgot affected the relationships in your family?

**Hanna:** It's clear that it has affected relationships, primarily between my husband, Ulric, and me. Already at BB we had a brochure that included all problems that could occur, with heart failure, dementia and other things. And so, at the end, it said that divorces are more common when you have a child with Down's syndrome. When we got the twins then we also received a brochure. Again it said in the end that divorces are more common when you get twins. It was not that encouraging!

Ulric and I are quite different, but we can not change each other. Wilgot requires structure and we must constantly think so we meet him as much as possible. We need to communicate with each other.

**AM:** What is the relationship with Faith and Light meant for you?

**Hanna:** It has meant a lot! We feel that it is quite unpretentious to attend a Faith and Light meeting. It requires nothing. You do not have to prepare anything. Everyone who gets there, whether they have a disability or not, are all at the same level, because we all do the same things. It is very liberating and something that becomes a strong participation for Wilgot. He notices that we are all involved, and that it is not just something for him. We are there together and that means a lot.



## 12. Kornelia

**Anne-Mette:** Tell me about Kornelia and what it's like to be her Mom?

**Teresa Czczko:** Kornelia was born in week 25. Then she weighed 600 g, and was only 26 cm long. It was a tough time and is one miracle that she survived at all. The doctors could not examine her because she was so small, and because of all her infections they could not give her antibiotics. We visited her every day at the hospital and for every time she only got worse. Every morning when I was at home and had my breakfast I was afraid that this would be her last day. I felt worse each day, I was depressed and did not want to meet other people.

After three weeks a friend called us where we lived in Stettin in Poland. He told me about a man from Italy, named George, who could pray with us. I did not want this, but my husband persuaded me to go there. When we met George, he asked me, "Where is your faith?" I replied that I am in a very difficult situation, because my daughter is dying. He said, "I know! But where is your faith? If you just believe your daughter will survive When you visit her

tomorrow you must stretch your hands towards her and say, "In the Lord Jesus name, you Kornelia, will soon come home with us! "

The next day we went to the hospital and did as he said. Everybody looked at us as if we were weird. The doctor came and said outraged: "What are you up to? Her condition is a lot worse and you have to leave the room right away! "But despite what the doctor said, we felt a peace within us when we left home.

The next day we decided not to go to the hospital, but stayed at home, praying for Kornelia. When we went to visit her the next day we did not find her in her room. We thought, of course, that it's over now. Now she's dead. But then a doctor came and asked, "Who are you looking for?" We replied: "Kornelia!" The doctor replied, "Kornelia is cured! She needs not stay in the intensive care department anymore. She has begun eat to and the infection is gone. But she still needs to stay for some time at the hospital to recover."

Kornelia was born December 30, and had to leave the hospital in April 8, and it was the day she was initially calculated to be born. She was still very small, and weighed under two kilos, but she was very active and moving around. When we visited one of the best neurologists in Stettin, she said: "It is incredible that such a small child may have developed so much. This seems very good ".

When Kornelia was two months, she received several different vaccinations, and that was the reason for her stopping to develop as she should. But we were confident in our faith that because God had let her survive, so he would make sure she should live and grow up like other children.

But it did not really go that way. We prayed a lot for her, and one day we were told that George would come to Stettin again. When we met him this time I said, "Now Kornelia is two years old, but she still can not go. She gets a lot of help of habilitation, but I think it's difficult, because it takes so much time. I have completed my education and now I want to make a career. But it's not possible for the habilitation and everything else around Kornelia takes all my time ". Then he prayed first and then he said, not that she should recover, but that "Kornelia will testify about Jesus for the whole world! "But I was not interested of that. I wanted her to recover so I could make a career, and realize myself. I was quite new in my faith and did not understand much about what God wanted.

After a few years we moved to Sweden and now Kornelia really testifies for everyone about Jesus. In the evenings we usually have evening prayers together, the whole family and the assistant, and then she thanks God for everything she had been through during the day, praying for those who needs help. Once a week we have what we call "The House of Prayer", in our house, when we pray, sing and read the Bible together. Sometimes people come depressed and do not want to say thanks to God. But Kornelia says, "I want to thank God that I can stand when my assistant helps me!" Then they look at her and start crying and the depression disappears. They realize that after all, they have more to thank God for than Kornelia has. She really testifies about Jesus, that He lives and makes wonders, not only in her life, but also in others.

When she receives Jesus in communion, she is often so happy that she shouts loudly: "I'm happy! I'm overjoyed! " Then she turns around and looks deep into the eyes of the person

sitting next to her, saying, "And you?" Many people get a little embarrassed of her spontaneous way, others think: "Am I really happy? " Some feel guilty and come afterwards and asks: "Why is she so happy, she is disabled and can not go, she screams a little and do not really fit in? " Kornelia helps people to reflect on their own situation.

She often says, "Mom, I'm so lucky I'm alive!" Now when I look at my life, I realize that the most important thing is not my career, for now I understand what God wants to do through Kornelia.

**A-M:** You have not been in Faith and Light for so long, but can you say something about what Faith and Light means to you and Kornelia?

**Teresa:** In the summer camp we have met many believers with disabilities, and Kornelia feels that they have the love of God in them, and it is a gift. And we are happy to be with people who want to pray. That's wonderful!





### **13. Jesus is the Way, the Truth and the Boat**

"Jesus is the way, the truth and the boat!" That is how we start the Faith and Light gatherings in Ål, Hallingdal, Norway.

We love the boat that is the emblem of Faith and Light. We have made a picture with the Faith and Light boat, where everyone has their face in the boat. We have had the emblem on many different birthday gifts, key rings, candles and refrigerator magnets.

Jesus is the way, the truth and the boat. It's not the way it says in the Bible, but for us, the boat is so important, that we think Jesus does not mind us saying that. The boat is so safe when Jesus is in it, so we will be there. The boat we have with us when we begin the meetings, and it is often included in the prayer time. Ruben, who does not always have so many words, can take out a picture from the pocket and show up when we talk about it.

We are a group of about 20 people. A faithful group. We have been in Faith and Light for over 10 years. But before that we had a group that met once per term. Now we meet the last Monday of each month.

We always start saying "welcome" to each one. -Hi Åshild! How nice that you are here! -Hi Arvid! So nice that you are here! In that way, everyone are greeted, and we learn the names. Many in the group express how good it is that everyone is seen.

Then we take a round where everyone tells us something about what has happened since last time. It can be both good and difficult things. That round takes some time and it's very nice to hear a little from everyone.

One can tell that he has become aunt or uncle. Some have been dancing. Another tells that she is going by train, and then Anita can ask if the person has remembered to buy a ticket. Then she says: "They will be happy when you come". Anita often asks and comments the

good things, so that important details appear in a story. One says that he / she is glad that the snow has come, but most of us are happy when the roads are not slippery. Another says he has been in the barn, and one has been with his father in Sweden.

The group is faithful and we look forward to meeting each other. Åshild says that for her it is "one before and one after Faith and Light". She thrives very well there, and she always prioritizes Faith and Light. She thinks it's both important and cozy. Åshild was born in 1979 and says that when she was two years old they discovered a tumor in her brain. She was operated a number of times, but the tumor is not completely gone. Therefore, she can still struggle with headaches. Then she tells that when she comes to Faith and Light, the headache often disappears, if not totally so at least most of it.

The group consists of people with both visible and not visible injuries. Therefore, we all feel that we fit in. In the Ål group there are not so many who are in family with each other. It's only one mother with an adult son, or it's volunteers who come and join and help with practical things. Some people has assistants, and they can vary, but we find that everyone who comes supports and is part of what's happening.

We have focused on being part of a large community, with many Faith and Light groups around the world. We can spend a few minutes each time to talk about it. We are prayer partners with a group of Faith and Light in Vesterbro, Denmark, and it is nice to have fellowship with them in that way. They have sent us photos and cards that we can look at.

Often Åshild reads a poem. She has two favorites and they are Footsteps in the sand, and The ant, by Inger Hagerup:

*Small?  
I?  
Far from it.  
I am just big enough.  
Filling myself completely  
along and across  
from top to bottom.  
Are you bigger than yourself maybe?*

A great experience is the Consert of the Year. We invite someone to come and play, and now it has become a tradition that it is Music for everyone. We in Faith and Light are a "fellowship for all". And music for everyone is for everyone who wants to play in a community. It is a group from a neighboring municipality that meets once a week. Everyone plays something, a triangle, a rhythm instrument, a tone on a xylophone, and some sing. Marta-Maria directs and makes sure everyone comes in the right place in the song, and Arild with bands has a solid foundation in the music, so it's an experience where we all get tears in our eyes, and are so happy for everyone who does such an incredibly good performance, depending on his abilities.

Liv-Kjellfrid is the mother of Ottar, and she is in the Board of Faith and Light and does many practical things. Ottar often has many thoughts in his head at the same time, and he

brings us all the details of what's going on. He talks a lot and can be restless in his body. We may think it might be tiring to take in so many impressions and thoughts into the head at the same time.

Liv-Kjellfrid says that since he was little he calmed down when he entered the church. He likes to attend worship services and he is faithful in Faith and Light. He likes routines. It seems like it's safe and good that we do the same thing every time. He knows what's going to happen. He is often ahead of what's going to happen. For example, when we go from a joint gathering to church, he is the first to wear the jacket and take place in the church where we have the prayer time. Or when there is a communion in the church, he walks first of all, preferably before the priest, and says, "Come, because everything is ready!" For Liv-Kjellfrid, it is extraordinary to see that everyone can be themselves. It's the fellowship Ottar functions best in. There are not so many other places he "fits in", but here he likes it.

He even likes the games we have. Everyone takes part in their own way, so it works well and it's a joy for Liv-Kjellfrid. It's like we're a big US. Everyone contributes in their own way and is accepted anyway.

Arvid began in Faith and Light about three years ago. He tells that it is only now that he has made friends and fellowship. Arvid was born in 1951. When he was 12, he was sent to an orphanage in Hønefoss and lived there until he became 18 years old. He says it was a difficult time for him. Yes, there are many bad memories. But it's history, and Arvid likes to tell about it, but he is happy that life has changed in recent years. It was after he grew up that he started making friends. He was invited to Faith and Light, and Arvid looked forward to each time. It is even so that he found two childhood comrades in Faith and Light. They were in the same class at primary school. After one year as a member he joined the Board of Faith and Light, and he is pleased with that.

We are a bunch that are very different, but the big thing is that everyone can fit. It is quite natural that everyone can be as they are. -Hei! Knut Herman shouts when he sees someone he knows, and he comes with a happy call when we go to church and when we pray "Our Father". Anita is good at asking anyone who tells something, both in the meeting and in the church during the prayer time. Ruben comes with his good smile and is always prepared to tell something about what has happened since last time. Embriks warm heart warms us all. He is good at recognizing and remembering everyone. It's good to have a small conversation with Embrik, the best we can talk about is Jesus. Kåre brings his accordion, and likes to play a self-composed tune. He presses a few buttons, draws in and out, plays for a long time, but he has a plan, and it ends with a crescendo and a shout: -Hi!

After the gathering we eat some food. Then we go to church. At the front there are chairs where we sit. Ottar comes in first. Then there's live flute music when everyone walks in. Åshild says she thinks it's great that there's live flute music when you get in. It becomes both solemn and holy, and at the same time it becomes close and simple. When everyone is seated, the flute is silent and the deacon welcomes you. Then we sing this song every time:

*In God's Father's hands, I am happy and free.  
Safer can not be anywhere.  
The heart that is wounded, the will that is divided;  
He puts everything in place and does it all.*

*Behold, God's Father's hands are kept as a boat,  
There is room for both smiles and crying.  
These good hands, they were nailed firmly  
like the red sail of life on the mast of death.*

*Ref: In the presence of my savior, the heart finds peace;  
He provides shelter without care.  
In the presence of my savior, the heart finds peace;  
every flower on earth gets light from his sun.*

Then it's time for prayer. We pray for Faith and Light in Denmark and in Aleppo, and others we think of. We light the candles in the light globe and the flute music plays again. Anyone who wants to go forward, can light a candle and pray a prayer. Sometimes someone needs some help, and then Åshild or someone else asks if someone needs help. Then there is one who is invited to have Faith and Light thoughts.

Knut Herman says -Hey! to the one to speaks. Sometimes there is a small conversation, a question or a comment. Knut Herman shows joy and says JAA when we come to "Our Father."

This moment is a sacred moment.

God is near.

Then it's over.

Ottar blows out the lights, as the faithful church servant he is.

*Heidi Langegard*