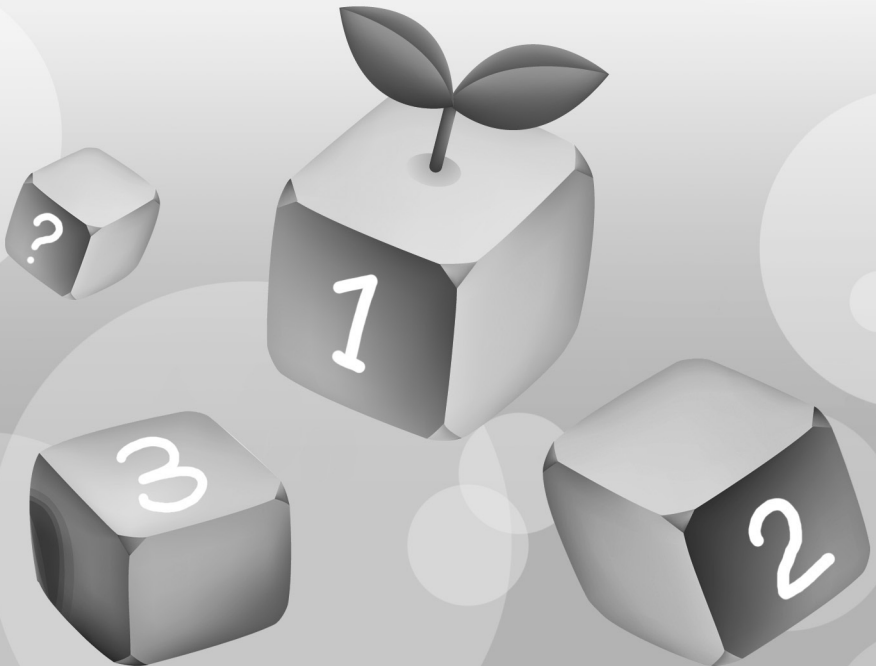


Class Notes

## Lesson Three

# Priorities

We had been very busy people. However, because of you, we were given the special opportunity to push our ourselves even further, and to learn how to prioritize the more important aspects of our lives. You helped us to become aware of the extent of our potential.

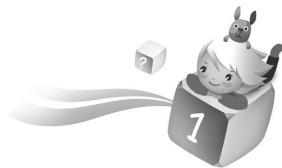




Loving sisters: Xin Xin (right) and Qing Qing.

Returning from the hospital, we wondered whether we should have you bunk with us or with your two-year old sister Xin Xin. We thought about it for a while and decided that it would be better for you to sleep in a room with with Xin Xin. We wanted to give her an opportunity to get to know you better because the two of you were to become travel companions on the long road ahead. We also hoped that one day Xin Xin would be able to help us to look after you. We hoped that your arrival would enrich her life rather than suddenly make her feel isolated. It is said that when a second child comes along, the first child tends to become jealous and attempts to compete for the parents' attention. Now that we had to spend so much time looking after you, we truly hoped that this would not make Xin Xin feel she was just left to fend for herself. Instead, we hoped that we could all join together to form a team; the whole family standing and working together as one.

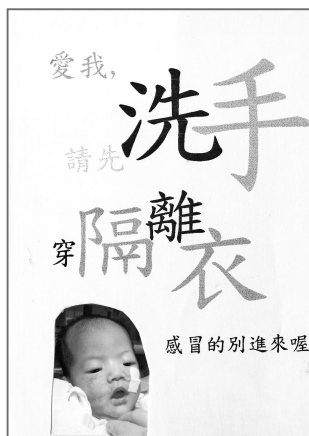




March 8th, 2005, you finally arrived home! We had set up the Family Intensive Care Unit in order to be ready for your arrival. (Please wash your hands and wear an isolation gown before entering. Don't enter if you have a cold.)

Ever since Xin Xin was 2 months old, we made her sleep on her own, and in her own room. In order to help her look forward to bedtime, we would always spend some time together before going to sleep each night. Of course, the first few nights that she slept alone, her crying was loud enough to wake the neighbors; but after she realized that we weren't going to give in, she learned to accept the situation and be self-reliant.

Xin Xin had already grown up to be an independent little girl and has developed her own opinion about many things. However, by observing her interactions with other children in Sunday school, we began to realize that she might be in need of a more permanent companion. When you were still in Mommy's belly, Xin Xin would occasionally try to give you a hug, and after you were born, she really wanted to have the chance to see you come home. However, since you had to stay in the hospital, she was



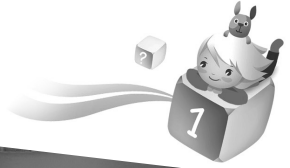
only able to look at pictures of you; she didn't feel as she had a sister just yet.

In order to be ready for your arrival, we rearranged the furniture in your little room. Of course, Xin Xin kept her little area the same as it had always been; I put my desk and computer into your room so that I could look after you and study at the same time. The crib that we had prepared for you had to be adapted into a little sickbed surrounded by the pulse oximeter, suction unit, air purifier and heater. Disposable materials, such as diapers, connection tubes for the suction unit, sterile gloves, feeding syringes, Q-tips and clean towels were all collected together and kept close at hand. We even hung some clean white shirts on the back of the door so that visitors could use them as isolation gowns when they entered our little Family Intensive Care Unit (FICU). Everything was in order, and we were just waiting for you to arrive.

## **I love you, Qing Qing!**

March 8th, 2005, you finally arrived home! We were so grateful that the day had finally come. Mommy and I were very cautious bringing you back from the hospital. We kept our eyes on the dial of the pulse oximeter the entire time. Actually, your condition was more stable now, so we could watch how Xin Xin would receive you. Would she be





Xin Xin rushed to hold you in her arms, yelling excitedly, “I love you, Qing Qing.” On the one hand, we were relieved to see her loving affection for you, but on the other, we couldn’t help but tease her saying, “Do you really know each other that well already?”

jealous? How would she greet you? It turned out that she rushed to hold you in her arms, yelling excitedly, “I love you, Qing Qing”, and then she gave you a quick kiss on the head. We were relieved to see her loving affection for you, but we couldn’t help but tease her saying, “Do you really know each other that well already?”

We quickly placed you in bed in the proper position; it was time for your lunch. This would be the first time that we had to figure out the nasogastric feeding tube without the help of the nurses. At first, we were

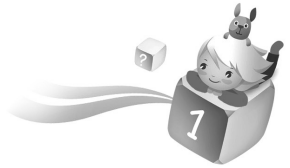
Qing Qing's muscles were not strong enough to swallow properly. Daddy would give her one or two drops of water with a spoon in order to help her practice swallowing.



very concerned that the feeding was going too fast and that it might cause you to vomit. If that happened, due to the fact that you still couldn't swallow properly, the vomit might go into your lungs and may even lead to aspiratio pneumonia. We were so concerned for your safety that it took us a good half hour to complete a 60cc. feeding. Fortunately, everything went smoothly during your first meal.

After the feeding, while you were taking a rest, we took the opportunity to unpack the things that we had brought from the hospital, and discuss the daily care schedule. Time was tight; we still had to perform the chest percussion therapy and use the suction unit to help break up, and remove, the phlegm from your chest; once that was finished, it would be time to feed you again. Day and night, we performed these steps over and over again in a three-hour cycle. We even had to find time to bathe you and help you to do some physical therapy. We also had to make sure that you





did not get bed sores, so we adjusted your position in the crib every hour.

It's almost impossible to imagine that Mommy and I were able to do all of this on our own. However, it was just like climbing a mountain: we could not keep thinking about how much farther we had to go, we had to just keep going, and in the end we would be amazed by our potential and by the scenery, all the more beautiful in the face of the tribulations that we had to endure.

That first day, we were as busy as bees, bustling about in the FICU, taking turns, one of us performing the different steps necessary for your care while the other rested. A lot of our friends were coming and going, expressing their sympathy, and bringing us homemade lunches. We were able to get through it all in one piece, but after all, it was only the first day.

## **A Friend in Need is a Friend Indeed**

Fortunately, there were always people who would come to help if need be. The saying 'a friend in need is a friend indeed' is an excellent description of all the good friends that would come and see you during those difficult times. During those early days, many of our friends from church who were nurses, or had been nurses in the past, sided us, offering timely assistance, and helping us to sharpen our own newly

Qing Qing receiving her daily massage from a small group of graduate students from our church.

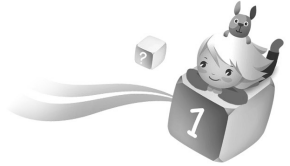


learned nursing skills. Although we did not have so many questions before, we now had loads of things that we wanted to discuss with them. For example, no matter how carefully we attempted to do the chest percussion therapy, on that first day it was still obvious that the procedure caused you quite a bit of discomfort. In fact, it turns out that we were doing it incorrectly. When our nurse friends demonstrated the procedure for us, they were able to do it with such ease that they could even chat with us while proceeding in such a way that you were comfortable enough to drift off to sleep. Moreover, these friends even offered to come over and help us once in a while so that we could take a much-needed break. When they offered, we were so tired that instead of being able to give a reply, we could only smile, eyes barely open, to show our appreciation for their kindness.

There was also a lovely group of graduate students who told us that although they were not nurses, they were experts at pulling all-nighters,







and that they could do their studying at our house in order to help keep an eye on you through the night; if anything went wrong, they could just wake us up to come and help. Although we appreciated their offer, we still felt that it was important for us to fully understand your entire twenty-four hour care cycle before deciding which times would be most appropriate for others to come in and lend a hand.

During the first week, although we were becoming more and more experienced with our nursing duties, our energy reserves were diminishing, and our life was truly being turned upside down. Trying to fulfill our duties as your parents was not as easy as we had imagined it would be. Apart from looking after you, we still had other duties to take care of: we were leaders in church; I had to write a thesis and take a qualifying examination; Mommy had to take care of Xin Xin as well as teaching at church. We could hardly handle our daily routines let alone find time for leisure activities or entertainment. We began to realize how difficult it actually is to act as caregiver to someone who has a chronic illness and is confined to bed. However, this was not the time for self-pity! We had already given our word that we would do all that we could to ensure that you were able to be a happy little patient; How could we break down now? We had to find a way! Furthermore, you were so valiant, making progress little by little. We too needed to bring our

determination and bravery into full play.

Of course this determination and bravery does not come without certain considerations. We realized that we could not go on like this, burning the candle at both ends, for an extended period of time. Looking at you, I knew that I had to leave the house and go somewhere else to say my prayers. I needed to be guided by the Lord who had brought you into our family.

Coming home, my mind became as clear as Moses' when he brought the Ten Commandments down from Mount Sinai. I told Mommy that we needed to make a proper schedule, not only to organize care rotations, but also to help prioritize all aspects of our lives.

## Priorities

To make you happy, we needed to do more than just take care of your physical needs. Your soul also had to be stronger than the average person in order to fully appreciate the fact that you too were a beloved daughter of God. Our Lord created you as one of a kind, offered you His unconditional love, and made wonderful plans for your life. We also wanted what was best for you. However, if there was a time when we could not be with you, we felt that the faith that was gradually forming in your heart would grow to become the most important conviction





I hoped that Mommy and I would grow to love each other even more because of you, and this would allow you to realize that your own difficulties could bring together those that love you. In this way, you could come to see your difficulties as a type of blessing.

in your life. In fact, we also needed to have this sort of insight in our own lives. Only when positive faith would become the guiding force in dealing with issues in our home could we find happy resolutions to life's many difficulties. That's why we were unable to let you occupy the first and foremost position in our lives. That place was, and always will be, reserved for God. We felt that if we place your needs above all others, you might think that you were the center of the universe. No matter how healthy your body were to become, if you were to hold this mistaken view then there would come a day when, while exploring the world, you would realize that you were unable to get what you wanted or unable to control things, and it would cause a heavy blow to your spirit. If that

happened, your world would collapse around you. As a matter of fact, you were not the most disadvantaged person in the world. You would have to find a way to live a meaningful life and even learn to help others. We had made a promise to you that we would never lose sight of the needs of others just because of you and we would not forget that God could love and take care of you even better than we could.

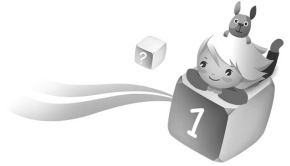
Therefore, we were determined to try our best to seize any opportunity to go to church, read the Bible, say our prayers, and continue to join our fellow Christians in those activities that helped to reaffirm our faith. After all, we are human, and our love is not inexhaustible; but we would still endeavor to get closer and closer to the source of this love in order to be able to continue to nourish you with as much love as humanly possible.

So, you were not our first priority. In fact, you were not even our

### *A Note From Mommy* 2005.3.13

Today, for the first time, I had you all to myself. Looking down at you I started to consider the many great challenges that lay ahead of you, and tears began to roll down my cheeks. Amazingly, you also began to cry; it was as if you were able to truly appreciate how I was feeling. You seem to be very sensitive to the feelings of others. I quickly wiped the tears from eyes and smiled down at you. You too had stopped crying and began to sleep comfortably.





second priority. When Mommy and I were married ten years ago, we made a promise to one another that we would never allow anything to come between us until death do us part. Of course, we could not allow our love for you and your sister to cause us to break this promise to each other. It has been our experience that in some families where there is a child who suffers from chronic illness, due to the fact that the parents must spend a lot of time and effort to care for the child, or are busy trying to make a living to support the family, they tend to neglect one another, causing them to grow further and further apart and even finally resulting in divorce. Although these loving families had done what they thought was best for the child, the result was often one that everyone would come to regret.

We were determined to avoid this sort of situation because we knew that if you were to blame yourself, or your illness, for any bad feelings that arose between Mommy and I, you would be unable to grow into a self-confident young girl; there would be no happiness in that sort of life. Actually, I hoped that Mommy and I would grow to love each other even more because of you, and this would allow you to realize that your own difficulties could bring together those that love you, and that in fact these difficulties would turn out to be a blessing.

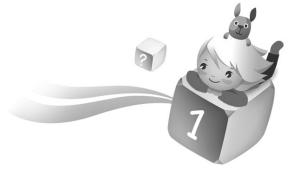
Last but certainly not least, your sister and you would come to occupy

the third most important place in our lives. Of course, it was not an easy decision to place you, my delicate little daughter, in the third position, but I knew that this would help you to be grateful for the fact that your life had truly been built on a firm foundation. This was the best way that I could think of to love you.

So, we rearranged our schedules based on these principles. We planned that meeting with the church would take priority, and if your condition permitted, we would take you along with us; if not, Mommy and I would take turns looking after you at home. We also decided that Mommy and I would go out on a date every week; even if it were for only an hour, we would find someone to take care of you so that we could relax or just have an intimate chat. Finally, in order to ensure that I was able to give ample attention to your sister as well, a certain amount of my time every week would be reserved exclusively for her. During this time we could read stories, watch cartoons, play computer games, or just go to the park together. It wasn't much, but having planned it all out in advance gave us a sense of stability, and helped to set our minds at ease that caring for you would not cause our lives to fall into complete disarray.

## The Night Shift





While I stood there holding you in my arms, not fully recovered from the fright of the incident, my hair a mess and my eyelids still swollen, Mommy, quite admirably, had the wherewithal to snap a quick photograph of us.



Since we had to spend a lot of time caring for you, Mommy and I decided to divide the duty shifts between us. Mommy was responsible for most of the daytime care while I was responsible for the night shift that lasted until 5:00am. This arrangement worked well because I was able to make use of the time to study and work on my thesis. I still remember the day, shortly after finishing my shift and handing things over to Mommy, I was lying on the bed, dead to the world, when suddenly I heard Mommy shouting my name; you had thrown up some milk and it had caused you to choke to the point that even your lips had begun to turn blue. I jumped up from the bed, rushed into your room in a panic, and grabbed the tube from the suction unit even before putting on the sterilized gloves. Thank God, after I had removed the mucus from

your esophagus, the numbers on the oximeter began to return to normal levels, ninety percent instead of the frightening fifty something that it had been, and the color came back into your cheeks.

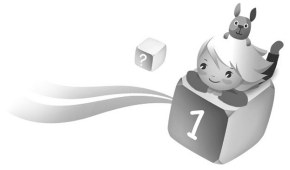
To my surprise, while I stood there holding you in my arms, not fully recovered from the fright of the incident, my hair a mess and my eyelids still swollen, Mommy, quite admirably, had the wherewithal to snap a quick photograph of us. She said that it would make a great addition to the records and memorabilia that we were collecting for you. Actually, the picture ended up winning us an award in the Father's Day photography competition held by the Taiwan Foundation for Rare Disorders (TFRD). The picture was used to share our experiences with other families, and tell them our stories of looking after a child suffering from a rare illness.

## One Happy Family's Secret Weapon

Working in the church, our working hours were very flexible. Except for the time that we spent with the congregation and in meetings, we were able to work at home to offer classes, consultations, and Bible-reading guidance. Although it was often necessary for us to interrupt our work to address some of your needs, working out of the house still allowed us to take care of both work and home as well as increasing the







Yi Han, a recent nursing school graduate, would often come to visit you. Once she became more familiar with your condition, since she had professional training in the field of nursing, we would sometimes allow her to take over certain aspects of your care.



number of people around us who understood your condition, supported you and were there to watch you grow up.

In those days, although we would not allow anyone with a cold into see you, our home was still always full of visitors. They would bring you get-well-soon cards filled with best wishes and encouragement. Jia Xian, a member of the church and a graduate student studying in the Biochemical Science department at the National Taiwan University, would visit you everyday to give you rehabilitative massage while you were still in the hospital. When you came home, she started coming to the house everyday to continue to give you massage. We were truly indebted to her for her kindness. There were also others who were very helpful; for example, Rui Fang and Jia Lin who both had experience nursing, as well as a recent nursing school graduate named Yi Han. Since they all had professional training in the field of nursing, once they

## *A Note From Mommy* 2005.3.27-4.20

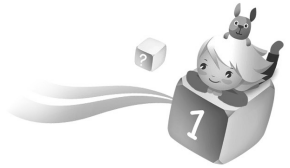
- We are very grateful for all the help that we have received over the past little while. For example, Jia Lin came by to help us learn more about the suction unit and chest percussion therapy, while Rui Fang taught me the best way to bathe you. Bright and early every morning, Daddy and I, still sleepy and bleary-eyed, enter your room to
- begin the daily routine: changing diapers, suctioning, chest percussions and tube feeding. Afterward, if the weather is good, I often take Xin Xin and you to the park nearby to enjoy the sunshine.

were more familiar with your condition, we would sometimes allow them to take over certain aspects of your care.

Aside from the help of all these great friends, there was also the support that your Grandparents offered. Although they were not able to directly assist with your care, they still cared about you very much, and would sometimes bring over delicious food for us to enjoy, or help by taking Xin Xin out to play so that we could have some time to rest. Some full-time homemakers from the church would also take turns taking Xin Xin out to play during the weekdays. Your sister really had a good time during that period; she always looked forward to going out to different places to have fun everyday. It was thanks to you that her life was enriched in this way.

Xin Xin really loved you dearly. The first thing she would do after waking up in the morning would be to go over to you and say good morning. She was always very considerate. If we were busy feeding you,





Xin Xin was always trying to be helpful. She learned how to wet a Q-tip and moisten your little lips.

she would just wait patiently for her powdered milk while we finished caring for you. Sometimes she even wanted to help us so she learned how to wet a Q-tip and moisten your little lips. She also learned to read the numbers on the oximeter, which was an added bonus because she learned to read double-digit numbers at a very early age.

In this way, we had cautiously eased our way out of the woods and learned to adapt to a life filled with challenges but also full of substance. The schedule that we had designed to give us some much-needed breathing room had begun to serve its purpose and help to bring order back into our lives. Even though there were times that we had to make adjustments to the schedule in order to cope with unexpected events, we still knew that this schedule was our secret weapon in fighting the long-term battle with your illness. The truth is, whether you were by our

side or not, we were always very busy. However, we still feel that it was thanks to you that we were given the special opportunity to push our limits, and to learn how to prioritize the more important aspects of our lives. You helped us to become aware of the great extent of our potential.



Class Notes

## Lesson Four

# There is No Fear in Love

At a time when the results of our actions were beyond our control, the only aspect that we could be certain of and responsible for, was that of the motivation which guided our decision making process. In other words, it was not out of some desire to make our lives easier that we made the decision, but it is out of our fearless love for you that it was done.





Over the course of the two months that were to follow, you began to gradually put on more weight while continuing with the physiotherapy treatments on a regular basis. You were still not very strong but you were able to begin to express your happiness and excitement by waving your little hands at us. Whenever the weather was good, we were able to take you and your sister to the park for a walk in the sunshine. Even though your strength was building, and we were ever vigilant to try to keep you out of harm's way, as with any child, you too would catch the occasional cold.



Mommy sitting in the park holding Qing Qing. Qing Qing often looked like she was dozing off because her eyelids were quite droopy due to the weakness of her facial muscles.

The weakened condition of your muscle tissue made it very difficult for you to cough. Therefore, if you were to catch a common cold, which most children would be able to recover from without any bother, there would be a strong possibility that other, more serious, complications would arise. Since you would be unable to fully dispel phlegm from your lungs, the situation could become increasingly serious due to the

increased opportunity for bacteria to invade and multiply within the respiratory tract. If the phlegm were to thicken it would not only cover the lungs and affect the passage of air through the airways, but it might also begin to affect the exchange of oxygen and carbon dioxide across the air-blood barrier. In some cases the phlegm may even become so thick and sticky that it would remain lodged in the air-passages and cause part of the lung to become as difficult to inflate as a deflated balloon with its inner walls stuck together. We picked up most of this sort of knowledge from the medical staff at the hospital, but we had no idea at the time that these sorts of complications would soon develop in your own frail little body.

I remembered it very clearly that there was one particular day when Taiwan was hit by a very fierce sandstorm from Northern China. You didn't seem to be too bothered by it, you didn't show any obvious cold or flu symptoms, you were in good spirits and your blood oxygen saturation levels were well above 90 percent. Everything seemed to be fine except for the fact that you were having problems breathing. We were not really sure what to do, so we made some phone calls to the more experienced nurses in order to seek their advice, and just continued to monitor your condition, thinking it was not really anything too serious. You slept for most of the afternoon and evening, and aside from an accelerated





heartbeat there were no obvious signs of trouble. It was not until later in the evening when you woke up having more difficulty breathing, your eyes seemed a little dull, your hands began to shake, and your blood oxygen saturation levels began to dip below 90. It was then that we quickly called for a taxi and rushed you to the hospital.



Qing Qing being moved from the emergency room to the ICU.

During the ride to the hospital, I carried your portable oxygen unit while my gaze was constantly fixed on the pulse oximeter. Since you were still having so much difficulty breathing, your heart rate continued to climb; that in turn made me very nervous and caused my heart to pound faster and faster too. Once at the emergency ward, the doctors immediately realized that your breathing was becoming more and more labored, so you were quickly rushed off to the ICU. While we helped to push your gurney down the hallway, we couldn't help but wonder how it was possible that your condition had deteriorated so rapidly and unexpectedly.

Once you had been admitted to the ICU, Mommy and I stood out in the hallway and waited. Everything seemed so quiet now compared



to the panic and chaos that we had just been through. It was a strange feeling; I was not sure what to make of it. I held Mommy's hand and we prayed. This helped to calm us down.

After we had waited for some time, the doctor finally came out into the hallway and explained that upon entering the ICU, you immediately went into respiratory arrest, and the medical staff did not have time to obtain our consent before making the decision to insert an endotracheal tube. Although your condition seemed to improve quickly thereafter, the cause of the initial and rapid deterioration still remained a mystery.

Even after a period of about a week, you were still dependent upon the endotracheal tube. Since the tube was not designed to function over an extended period, the doctor asked us to seriously consider the more long-term alternative of a tracheostomy: a surgical procedure that is accomplished by making an incision in the windpipe in order to enable the patient to breathe with the assistance of a ventilator, as well as making the airway easier to maintain. If the patient's condition improves, the ventilator may be removed and the incision would heal over. However, according to the doctor's evaluation, there was a good chance that if you were to go through with the tracheostomy your lungs would gradually begin to deteriorate. We feared that this would cause you to become dependent upon the ventilator for the rest of your life. That was obviously





not the future that we had envisioned for you.

## **A Tough Decision**

Due to the fact that your illness was an extremely rare one, the doctors, just like us, were only able to learn about your condition through experience. Some important questions still remained: In what way would these types of respiratory treatments help to improve your condition? As you aged, how would your illness progress and develop?

In general, the doctors were only able to offer us consultation pertaining to the treatment of the more common illness known as Myopathy, but no one was ever able to actually predict which treatments would work best for your more unique condition, Centronuclear Myopathy. Even something as simple as knowing when to rush you away to the hospital if you were to contract a cold again was the kind of knowledge that only came after we had nursed you through many more colds and engaged in many more discussions with the doctors.

Based on these experiences, Mommy and I gradually came to realize how difficult it actually was to make decisions about medical treatments. Furthermore, thanks to our experience with you, we also realized the tremendous weight that lies squarely on the shoulders of the parents of sick children. Financial issues were not our main concern since most

## *A Note From Mommy* 2005.4.22

Before you were moved to the ICU, the nurse had warned Daddy and I that you were now hooked up to a lot of different tubes. When I finally saw you, my heart ached; you were connected to a ventilator, had a suctioning tube in your mouth, a nasogastric tube in your nose, an IV in your right hand, a syringe in your left hand for taking blood samples, and the pulse oximeter attached to your leg. It was very difficult to see you like that.

of the expenses for treatment were covered by our national health insurance. Thus, it seemed that the most difficult aspect was the fact that the actual real-life ramifications of our decisions could not be predicted, and in the end it would be you, not us, who would be affected by these unforeseeable consequences. Perhaps the unpredictable outcome of these decisions would carry a heavy price for you in the future; your quality of life may be affected, or there may even be a negative impact on your chances of survival.

The main responsibilities of the medical staff at the hospital were to assist in the preservation of your life and to help us, as your parents, to better understand the options regarding procedures and developments pertaining to that end. But, since it was Mommy and I who actually had to make decisions regarding these different options, it would be the two of us, alone, who would have to shoulder the burden of responsibility





Mommy went to the hospital to visit you today (April 24th, 2005) and found that you had become much more lucid. Unfortunately, the most she could do for you was to gently wipe away your tears and pat your little head to try to comfort you.



that went along with the outcome of these decisions.

Although many of the experienced nurses in our congregation shared their clinical knowledge with us, and helped us to better understand the situations that might arise from the tracheostomy procedure, we were still not sure whether or not it was fair for you to go through such suffering. We just wished that you could speak for yourself and make the decision for yourself. However, watching you suffer from the pain caused by the endotracheal tube, we knew that we had to make the decision as quickly as possible.

## Facing Death

Who has the right to decide whether another person should live or die? How could we possibly make the decision to just let you go? If we

were to make such a decision, would it be one that we regretted for the rest of our lives? On the other hand, if you were not going to be able to pull through by your own strength alone, wouldn't it be more natural to just let your life run its own course up to the very end? Or, no matter what happens, should we continue to doggedly look to medications and medical machinery in hopes of extending your life? Eventually your body would begin to deteriorate, just as all of our bodies do. It is impossible to extend a life indefinitely. But is death really such a bad thing? After all, isn't it just ignorance that causes us to fear death? If it were your time to go, how could we be sure that it wasn't a call from God, bringing you back to His side, saving you from all that suffering? Our Dearest Qing Qing, it was such a difficult decision that had to be made!

Regardless of the extent to which medical science has advanced, the privileged and the underprivileged alike must eventually take leave of this world. It is true that medical science has developed to the point of being able to increase life expectancy by a dozen or more years, but ultimately we all still must face death. Moreover, trying to elude it does not necessarily ensure us a better existence. Instead, being able to accept the truth of our own mortality allows us to begin to contemplate how to strive for a more meaningful life. Those who fear death may be inclined to chase after the prospect of extending their lives. But when we factor in the





## A Note From Mommy 2005.5.8

- Today is Sunday, and it's Mother's Day. Mommy took the opportunity to share your life story with the congregation at church today. Although we have been through our share of difficulties, you are still my little angel, and you have helped me to grow as a person. After I had finished telling your story, many of
- the members of the congregation came over and told me how much it had encouraged them. Qing Qing, you truly are a little angel; you are able to inspire others to make positive changes in their lives.

importance of quality of life and the promise of an afterlife, everything changes, priorities shift. In making decisions pertaining to your care, we had to consider all of these different factors. There will come a day when we too will be called back to God's side, and in His infinite love for you, He will undoubtedly ask us why we made one decision instead of the other. We will have to offer some justification.

## **There is No Fear in Love**

It was through prayer that we gradually came to the realization that making this sort of decision was not just a matter of choosing the option with the highest probability of success or trying to make the right decision. In fact, since the ramifications of our actions would be totally beyond our control, the most important element must then become the nature of the motivation driving the decision making process. In other

words, this decision that we had to make was not made out of some desire to satisfy our own emotional needs, but instead, it was based entirely on our boundless, fearless love for you. At the time, the following passage from the Bible seemed to resonate strongly with us: “There is no fear in love, but perfect love casts out fear.” (1 John 4:18)

When we looked to the source of life, we began to realize that God is the only one with true governance over life and your destiny lay neither in our hands nor in the hands of any medical staff. The love that God gave to you was much more profound than anything that Mommy or I could ever have offered you. It is He who brought you into our family and it is He who would decide when to take you away. God has prepared a wonderful place for us all in Heaven, a place far more beautiful than anything we could ever know in this world.

We always felt that if it were possible for us to have more time together in this life then we would definitely appreciate and cherish it, but we also knew that it would be even more wonderful for you if God could end your suffering and bring you back to His side to bask in His boundless love. Of course, we would miss you very much if you were to leave, but we also knew that you would be going to a better place, a place without tears, a place full of happiness and blessings.

The fourth day after Mother’s Day, Mommy and I paid a visit to the





ICU. As usual, the doctors gave us an update on your condition and reminded us that upon removal of the endotracheal tube, if your condition were to worsen, it would become imperative that we make a decision regarding the tracheostomy. Although I had thought it over and already made my decision, it was still very difficult for me to discuss it with the doctor, especially since you were lying right there on the bed nearby. The words seemed so heavy that I was unable to spit them out. I tried not to look at your face. It seemed as if your glance would cause me to have reservations about the difficult decision that I was about to make.

I spent some time discussing our decision with the doctor and explaining how our religious beliefs helped to shape our views concerning your medical treatment. We also asked whether it would be possible to donate any of your organs for the purpose of medical science, if you were to pass away as a result of not undergoing the tracheostomy procedure. At that point, I glanced over at you and was suddenly unable to continue with the discussion.

## **Even Though You Are Still Here, I Already Miss You So Much**

The doctor acknowledged that she understood our decision. She then asked us to sign a DNR (Do-Not-Resuscitate) form, confirming that we



had chosen to relinquish the right to have you resuscitated in the event that your condition deteriorated. After that, the doctor allowed Mommy and I some time alone with you.

I sat beside you, holding your tiny, delicate hand. Your poor arms were so poked full of needle holes that they were all bruised. I bent down and sang your favorite songs softly into your little ear. My lips trembled as I told you not to forget how much Mommy and Daddy loved you. Looking into your bright, tearful little eyes, I could feel a lump forming in my throat. It was so strange, even though you were still with us, I had already begun to miss you. I missed you so much that my heart seemed as if it had been shattered into tiny pieces.

I looked at you intently, with the hope of engraving your image into my memory so that I would never forget it. Unfortunately, the more I gazed at you, the blurrier you became. Suddenly, I realized that it was the tears that I was no longer able to hold back that were blurring my vision. I looked at the tubing going into your nose and the many needle marks that covered your arms again. That is not how I wanted to remember you. Even though seeing you like that reminded me of all the pain that you had been going through, and of the fact that you were indeed mortal, I was still able to envision that you were now headed for a place in which you would no longer be limited by such shortcoming or





imperfections.

All at once, I began to admire you; your soul was so pure, so befitting of your destination. I knew that inevitably my body would give in one day as well, and I just hoped that my weary old soul would be able to hang on to its beliefs up to the very end that I would have the chance to meet you again.

As we rode our scooter home from the hospital that day, there was a slight drizzle in the air; meanwhile, under our helmets a storm brewed and tears streamed down our cheeks in torrents. When we arrived home, we began to discuss how to make the best of the uncertain amount of time that you did have left. We hoped to make you as comfortable as possible.

## Important Dress Rehearsal

### *A Note From Mommy* 2005.5.9

- Today, Daddy and I went to the hospital together in order to tell the doctor that we had decided that it was time to let you go; we felt that you should not have to suffer anymore. Daddy was saddened to the point of tears by having to make this decision. Neither of us wants to see you go; you are such a sweet, brave little girl,
- and we really wish that we could have more time with you. However, we both know that God loves you, and that He will guide you. Daddy says that he has already begun to miss you.

After a period of about two weeks in the hospital, although you were still having some difficulty breathing, your overall condition had begun to stabilize, thanks in part to the assistance of the oxygen unit. Thus the doctor finally decided to let us bring you home. We had originally thought that upon your returning home this time, it would only be a matter of time before you began to have even more difficulty breathing, and finally you would just not be able to go on. However, to our surprise you were once again able to exceed all of our expectations. Of course, during your first few days back at the house you were often quite uncomfortable but still, you persevered in silent determination. The odd time you shed a tear or two, but we only needed to moisten your lips with a drop or two of water and you would smile again in no time, cheerful as ever.

By the time another month had passed, you had already begun to make considerable progress. You were able to breathe without the assistance of the oxygen unit, wave your arms and legs about with greater dexterity than before, and even play with your toys. The next time we took you to the hospital for a checkup, the doctor just kept repeating the words “very good, very good!” She also reminded us to provide you with ample nutrients in order to help you to continue to grow stronger. It was totally unbelievable! Perhaps part of it was that it was so difficult to be able to





### Qing Qing's speedy recovery

fully, and accurately, evaluate the actual circumstances surrounding your condition: one moment things were

worsening, the next they were suddenly

improving. Of course, when it comes to the complex issue of a human life, only God can be said to have a true understanding. Therefore, we knew that this was an important dress rehearsal for us. The shock of realizing that you might pass away at any moment had offered us the rare opportunity to prepare mentally for the inevitable event that would one day take you from us, or in the case of our own deaths, bring us all back together at God's side.

In essence, both birth and death are very important aspects of family life. In traditional society, a child was born into this world in the comfort of the family home, the infirm or elderly passed out of the world in that same setting, with their loved ones all around them, and the deceased were buried nearby the home, or even right in the backyard. In contrast, in our modern society, with the proliferation of medical institutions, medical research, and the concept of city planning, death, originally a natural part

of human existence, has now become a phenomenon that is far-removed from family life. Nowadays, the average person's life will begin inside the walls of a medical institution and eventually end inside those same walls. It is sad to see that many of today's medical advancements have actually brought about suffering by obstructing the originally natural cycle of birth and death with a plethora of new, unnatural technologies and apparatuses. In the hopes of receiving effective medical treatment, most of us really have no choice but to yield to the onslaught of this double-edged sword of technological advancement. But, in the end, the family usually finds themselves in the unfortunate position of sitting outside the operating room hoping to have just one last chance to hold their loved one's hand and express their last sentiments as the final hour approaches.

## **Preparing to Face Death**

For most of your short little life, you had been surviving in an unstable state somewhere along the fine line between life and death, so we had come to accept the fact that your inevitable passing was not just something that was far off in the distant future. With each recurring dress rehearsal, we not only became stronger and more courageous but also began to establish a clearer perspective about life itself. When





we understand that death is a natural and fairly imminent reality of the human condition, we can begin to seriously consider how to live life to the fullest. We will be able to leave this world with a feeling of contentedness toward our mortal existence.

Having prepared ourselves mentally and spiritually for the possibility of your passing, each day that we spent with you thereafter became an unexpected bonus. With this open-minded attitude we were able to truly cherish the precious things in life. When even death does not intimidate you, there is really nothing left to fear. Adopting this sort of fearless demeanor, we started to live our lives to the fullest and to enjoy the blessings and happiness that truly belonged to us.

Mommy and I knew that when the day to say good-bye actually arrived, there would be nothing to fear because we would not harbor any regrets, we would have many loving memories to enjoy, and above all, we would experience the wondrous anticipation of being delivered into the Kingdom of Heaven.

During the short period of time that we shared with you, we learned that we should not just timidly float through life, absorbed in dealing with the hardships, but instead, realize the reality of death and learn to live a full, wonderful life without regrets. Fostering this sort of attitude helps to enrich our lives with courage and freedom.