Title: The 600-Step Program for Type 1 Diabetes Self-Management In Youth: The Magnitude of the Self-Management Task

Running title: Type 1 Self-Management Magnitude

Authors: Ronald D. Coffen, Ph.D., Andrews University, Associate Professor of Educational and Counseling Psychology

Corresponding Author: Ron D. Coffen
Bell Hall 206
Educational and Counseling Psychology Department
Andrews University
100 U.S. Hwy 31
Berrien Springs, MI 40104, USA
(269) 471-3491 (office)
(269) 471-6374 (fax)
coffen@andrews.edu

Word Count: 3896 Words (not including table, references and appendix)

Tables and Figures: 1 table
no figures
1 appendix

Publication Info: Coffen, R. D. (2009). The 600-step program for type 1 diabetes self-management in youth: The magnitude of the self-management task. *Postgraduate Medicine*, *121*(5), 119-139.

doi: 10.3810/pgm.2009.09.2059

ABSTRACT

This article demonstrates the complexity of the type 1 diabetes regimen and describes the physician's role in safely promoting self-management of diabetes by youth. Literature describing type 1 diabetes and the required regimen, issues related to regimen adherence by youth, demonstration of the magnitude of the regimen, and implications for physicians are addressed. A task analysis and tool for physicians is presented that contains over 600 tasks. Given the magnitude of the regimen, issues related to the physician's promotion of the gradual transfer of regimen control to youth are illustrated. The importance of understanding broad areas of the regimen (e.g., "insulin injection") as not one task but many is emphasized as is the need to explore adherence *within* regimen areas to pinpoint problems related to poor metabolic control. How managed care influences the approach that a physician may take to communicate the requirements of the complex regimen to youth and parents is also examined. It is concluded that a developmentally sensitive approach must be taken that promotes youth's internalization of the importance of regimen tasks and the article provides suggestions for accomplishing this in a gradual manner that promotes developmentally appropriate involvement of youth in the regimen without premature responsibility.

The 600-Step Process for Type 1 Diabetes Self-Management In Youth: The Magnitude of the Self-Management Task

DESCRIPTION OF TYPE 1 DIABETES AND THE REGIMEN

Type 1 diabetes results from an autoimmune response that completely and permanently destroys the pancreatic β-cells that produce insulin. This destruction results in hyperglycemia and insulin must be taken exogenously so that blood glucose can be transferred into cells to accomplish energy metabolism. After diagnosis, an initial hospitalization is typical to re-establish proper levels of blood glucose by establishing a daily regimen of insulin injections. Subsequently, maintaining metabolic control continues as a lifelong task for people with type 1 diabetes.

Metabolic control involves balancing insulin types, insulin doses, exercise and diet in an attempt to maintain normal blood glucose levels.[1] Research repeatedly demonstrates that children, and in particular adolescents, struggle with adequate adherence to the type 1 diabetes regimen.[2-11] Both physiological changes in adolescence as well as adherence behaviors impact metabolic control.[12] The American Diabetes Association (ADA) indicates that the primary goals of treatment for youth with type 1 diabetes are to achieve physical and psychological well-being and to promote normal growth and development.[13] It is the premise of this article that accomplishing physical and psychological well-being and normal development for these youth presents a unique challenge for the physician under the current constraints on the practice of medicine and it also requires mastery by the physician <u>and</u> patient of a myriad regimen details.

Although the complexity of the regimen is regularly acknowledged in general terms,[14-21] physicians not specializing in the management of type 1 diabetes may not be fully aware of the level of sophistication required of youth with type 1 diabetes to manually simulate the bio-regulation that had been the role of the pancreas. The complexity and effort required to follow this regimen may be underestimated, in part, because the specific tasks required have not been clearly delineated.

ADHERENCE ISSUES

The primary broad behavioral tasks involved in type 1 diabetes that are necessary for metabolic control involve a regimen of insulin injections (3 to 5, or more, per day), finger sticks to test blood glucose (3 to 6 per day), careful monitoring of diet, regular exercise, and immediate treatment of hyper- and hypoglycemia.[1,22-25] Annual comprehensive ophthalmologic exams, quarterly medical exams, quarterly venous blood draws, and annual 24-hour urine collections are necessary.[22-24] Good management includes not smoking and regulation of blood glucose, blood pressure, and blood lipid levels.[13,22,24] All this is required for those who have acceptable control already (i.e., those who have glucose levels in the acceptable range). Additional management is necessary for those in poor control. A negative spiral can result for those in poor control who may not perform the essential tasks to begin with and as a result end up being required to perform the essential tasks plus additional tasks.

In addition to the primary behaviors necessary for metabolic control, specific knowledge related to secondary behaviors is also required for adequate metabolic control.[22-24] For example, with insulin injection, insulin must not be exposed to extreme temperatures or excessive shaking. Mixing of certain short-acting and long-acting insulins changes the effect of the short-acting insulin. Proper injection procedures must be followed to ensure comfort, proper dosage, and sterility. Injection at different sites (e.g., abdomen, arms, thighs, buttocks) alters the rate at which the injected insulin is absorbed. Effective insulin treatment depends on understanding the actions of the various types of insulin (onset, peak, and duration times) and understanding the relationship of blood glucose levels to insulin, exercise, food intake, and stress.[22-24] Additional demands are placed on those who use continuous subcutaneous insulin infusion (CSII; use an insulin pump).[26] Thus, taking an injection goes beyond just the act of receiving a shot, but involves many secondary behaviors.

Nonadherence, errors, and miscalculations in the regimen can lead to both acute and long-term complications. Long-term complications include nerve and kidney damage, retinopathy, cataracts, atherosclerosis, hypertension, thyroid disorders, increased risk for infection, foot ulcers, and other related circulatory dysfunctions.[22-24,27,28] It is estimated that diabetic retinopathy is the most frequent cause of blindness in adults between the ages of 20 and 74.[23] Foot problems are a major cause of illness, disability (due to amputations), and death in people with diabetes.[23]

It is not a small group of children who experience these health risks. With three out of four new cases of type 1 diabetes being diagnosed in children and adolescents, it is among the most common chronic diseases in youth in the U.S..[23,29] Peak onset is between ages 9 and 12.[30] In 1981, Baker and Lyen reported that while 90% of individuals without type 1 diabetes would be alive after 35 years, only 50% of their peers with diabetes would still be living 35 years after diagnosis.[31] Twenty-five years later mortality rates are still high. Portuese and Orchard found that more than 15% of children who develop diabetes will die by age 40 years, a mortality rate 20 times that of the general population.[32] Prior to the mid-1980s the trend in mortality rates for those with type 1 diabetes was decreasing but appears not to be falling now.[32] Beyond just continuing to live, there are also quality of life issues. For those age 18 years or older, 28% of those with diabetes reported being unable to work and 42% reported being at least limited in their ability to work (compared to about 16% of those without diabetes).[33] Thus, physicians have a sense of urgency in motivating young patients to adhere with regimen tasks to achieve better metabolic control early on to reduce risks for diabetic complications.

THE MAGNITUDE OF THE REGIMEN

At first glance, one might assume that these high stakes would motivate youth with diabetes to take good care of themselves. Why, then, might that not be what is found? Why do youth struggle to follow the regimen designed for their own health? It is the premise here that it is due, in part, to the magnitude of what these youth are required to remember to do daily, even hourly, with no “vacation.”

Karoly provides a useful metaphor for the complexity of the regimen when he writes that “it is well to think of medical compliance as a complex multilevel skill *akin to such things as flying an aircraft* [emphasis added].”[34(p16)] When placed in such a context, the challenge for the physician of teaching during a few short office visits something as complex as how to fly an airplane is staggering. Some might argue that the focus on adherence is misguided given that “research has not revealed a consistent, robust relationship between treatment adherence and HbA_{1C},” but it is possible that the causal relationship is the reverse.[35(p307)] That is, the failure to fully take into account the complexity of the regimen may be the reason why strong relationships have not been consistently found. Until treatment adherence is assessed at the level of complexity that actually exists, research findings may continue to be of relatively small magnitude.

Even physicians working with these youth in the clinic every day can underestimate the magnitude of what is required. Warren-Boulton, Auslander, and Gettinger asked 65 health professionals (40 registered nurses, 11 dietitians, 7 licensed practical nurses, and 7 other health professionals) to simulate the diabetes regimen for four days.[36] All participants had been trained in the correct techniques for following the regimen. After four days, health professionals “almost always” adhered to the injection tasks only 58% of the time, but even on the first day only 87% adhered “almost always.” After four days of “having diabetes,” 42% did not adhere to the insulin injection regimen most of the time. Adherence rates for diet-related tasks ranged from 53% on the best day (day 1) to 38% on the worst day (day 3). For glucose testing, adherence ranged from 48% at best (day 1) to 18% at worst (day 4). And for recording results, adherence ranged from 57% at best (day 1) to 23% at worst (day 4). The study authors reported that at the end of the four days the participants (health professionals) were overwhelmed with how difficult it was to adjust their lifestyle to the regimen demands and that they adjusted their expectations for patients and reduced their judgmental approach. The health professionals came to recognize “the importance of allowing patients the time to learn and integrate the regimen into their lives, as well as the need to periodically provide contact for reviewing the details of the tasks involved”.[36(p539)]

To provide the physician with a specific and definitive reference for what skills the youth with diabetes must master (without a four-day diabetes simulation), the appendix presents the results of a task analysis that identifies in detail the demands of the type 1 diabetes regimen. Task analysis is the process of breaking a task down into the most basic steps required to reach a specified goal—a sort of recipe of components that are combined to complete a process. Very basic pieces of knowledge and actions required are explicitly identified. Each piece in the task analysis is required for the task to be completed properly. The task analysis includes both cognitive and behavioral components—what must be known or analyzed as well as what physical abilities must be present and what physical actions must be performed. If someone performing the task leaves out or does not have a piece then the task will not be properly completed. To develop the task analysis for managing type 1 diabetes, professional medical publications were analyzed as well as consultations with health care professionals such as diabetes educators who regularly teach the regimen to those with type 1 diabetes and also observations of children performing regimen tasks. Electronic databases were searched for measures of diabetes regimen adherence that specified regimen steps. Databases were also searched for best practices and practice standards recommended by professional associations charged with promoting research-based, quality administration of medical services to patients. Regimen tasks were conceptually categorized into broad areas (e.g., “Insulin Technique”). Within each broad area, specific actions and knowledge required were listed according to theoretical and empirical literature as well as according to conceptual and observational rationales (e.g., “Pulls plunger back to draw in insulin” would be a conceptually relevant step identified through observation of task performance even if not specifically mentioned in theoretically- or empirically-based standards in the literature).

The resulting task analysis for type 1 diabetes management integrates information and standards from multiple authorities.[13,22,24-27,35,37-48] Previous publications have been referred to as providing a “task analysis,” but tend to list only broad categories of areas that must be mastered (e.g., acquire knowledge, or, carry out planned regimen).[eg,49] The task analysis in the appendix provides physicians with a comprehensive list of knowledge that youth must implement, physical abilities that must be present (an action must be physically possible for the child before it can become a skill) and actions for managing diabetes effectively. It contains over 600 items.

IMPLICATIONS FOR PHYSICIANS

Developmental and Gradual Transfer

When faced with the 600-item task analysis, perhaps the first question that arises for physicians is how to promote the youth's mastery of the skills required to self-manage his/her own diabetes. When faced with mastery of more than 600 tasks, the answer must be: *Gradually*.

Childhood and growing up are developmental processes with rates of development of skills that differ across children. A chart identifying fixed ages that children should be doing various tasks is not feasible given individual differences. An example that is common to parents may help physicians guide parents in sorting out a developmentally sensitive but not age-dependent approach: How parents transfer responsibility for crossing a road can clarify the developmental issues in diabetes self-management. When a child is born, the individual success of a child crossing a busy street on his or her own is impossible. The parent carries the child across the street and is fully responsible for the task. As the child learns to walk, the child obtains the physical capabilities to cross the road, but individual success of accomplishing this safely is unlikely. The wise parent holds the child's hand as they cross the street together, and the parent explains the correct process to the child while it is being done. The child is told the principle or rule for the task in a way that the child can understand, but he or she is not likely to recall the principle or rule on his or her own yet. Soon the child can complete the entire task on his or her own, but the parent supervises the task closely and corrects errors with explanations that teach the principles behind the appropriate behaviors. Here the child may walk beside or in front of the parent while crossing the street and responsibility is shared. The child can recall the principle or rule when asked, but may still need prompting to apply it. Then, there comes a time when individual success is likely. The child can recall and apply the principles appropriately, spontaneously and independently and may be given (should be given) complete responsibility for the task. The child's skill is demonstrated as knowledge in action.[38] Parental involvement at this point is inappropriate except for occasional monitoring to verify the child still performs the behavior(s) correctly or in unusual situations.

The process of transferring responsibility for control involves a progression that is, ideally, gradual and supervised.[25,43,50-53] There is a time when (A) adults (parents and physicians) are completely responsible, (B) a time when adults prepare the child for responsibility, (C) a time when adults supervise the behavior, and (D) a time when adults transfer complete responsibility to the child. Physicians apply a similar process to the much more complex regimen of diabetes self-management (see Table 1). To promote the development of skills (knowledge acted upon), youth need a gradual transfer of control.[cf,2,11,15,50,54-57] Aspects that children are capable of doing should be transferred, but not a whole regimen area at once. Even very young children are capable of some aspects of a regimen area (e.g., using alcohol swabs to clean vials and injection sites), but even adolescents may not be skilled at all aspects. According to Derry, "procedural skills are likely to be accessed and used spontaneously only if they have properly evolved through practice, and if conditions that indicate their applicability are clearly understood."[58(p348)] When youth are not fully responsible for an aspect of the regimen, they should be in training to take on that responsibility by participating to whatever extent possible. "More adherent children tend to remain more adherent...as they enter the adolescent years."[25(p285); but see 12] Thus, physicians should encourage youth always to be involved, but help parents to understand that youth should not always be responsible.[35,50] By promoting youth involvement, physicians seek to ensure that youth understand the relation between insulin and glucose and exercise and diet, between sterility and wellness, between air bubbles and dosage, between timing of shots and timing of snacks. Involvement uses guided participation in real-life experiences to gradually build requisite skills. Responsibility removes participation of adults which must come when skill is demonstrated on individual aspects of the regimen, but involvement in all areas is a prerequisite to responsibility. The task analysis presents a tool for exploring the transfer of responsibility for some aspects versus involvement in others to produce a gradual transfer process.

One Is Many

Gradual transfer can only be accomplished when it is realized that broad areas of diabetes self-management are not single tasks, but multiple tasks. The task analysis helps to keep that reality in focus. Current literature lacks such a comprehensive list and nearly universally presents fewer than 100 items and most typically presents about 25 items.[2,18,55,59-90] The insulin injection process alone involves about 40 steps and that does not include the multiple pieces of knowledge that must be used to determine the appropriate dose, whether or not one may safely exercise before or after the shot, how various food-effects will impact the insulin's effect (e.g., the difference between a high fat versus a high starch meal), and how stress or illness might impact the appropriateness of different decisions.[cf 24] Physicians may lose sight of the complexity and magnitude of the regimen if the regimen is referred to in large chunks (e.g., “insulin injection”) instead of identifying the multitude of specific tasks involved in each major area of the regimen. Forgetting the complexity can result in inappropriately interpreting a patient's lack of regimen adherence as oppositional, lazy or apathetic when it may be related to feeling overwhelmed, an incomplete understanding or forgetting due to the demands on memory.

Problem-Solve Within Areas

Because of the magnitude of the regimen, it is more reasonable for physicians to ask patients about adherence to specific aspects of regimen tasks (e.g., specific line items in the appendix) rather than asking about regimen adherence to broad areas (e.g., appendix headings). When metabolic control (e.g., $HbA1_c$) for a patient is poor, instead of asking if a patient takes his/her injections and receiving an answer of “yes” which implies perfect adherence, the physician can ask about the specific aspects of the injection task to pinpoint where a problem *within* adherence may lie. The physician could even ask the patient to demonstrate the performance of a regimen task and, comparing that performance to the task analysis, could identify where a problem or problems within adherence may lie. Of course, the physician may also discover there is no problem with the performance of a specific area and move on to other solutions, e.g., modifying dosages, timings, activity levels, diet, etc.

Multidisciplinary Teams

Physicians are faced with the challenge of helping youth with type 1 diabetes and their parents skillfully apply the details of the regimen while simultaneously working under the constraints of managed care. Creer points out that most patients visit with their physician for only about 7 minutes (up to 12 minutes for a new patient) during an appointment.[91] It is difficult to convey the intricacies of the complex regimen to patients and parents during 7-minute visits with their primary care physician. Even if physicians spend longer with patients with complex chronic conditions, considerably more time than 7 minutes is required to accomplish the transfer of understanding of the regimen and the implications for following the regimen to patients and parents. Creer aptly notes that a market-driven health care approach tends not to meet the needs of patients with a complex chronic illness. A different approach is required when treating acute disease versus complex chronic disease. An individualized, problem-solving approach is needed that involves more frequent visits with the physician who mentors patients and parents in the analysis of diabetes-related data (e.g., daily blood glucose results) so that youth and parents learn how to adaptively manage the daily demands of diabetes.[50] More frequent physician visits increase the opportunity for the physician to educate the patient about the details of the regimen and to use the patient-physician relationship that develops to motivate adherence (relationships are a strong motivator for compliance during adolescence). Telephone contacts in between clinic visits are another possibility but difficult to get reimbursed for. For most patients, complete education will be accomplished in a collaborative team approach among and across physical and mental health professionals including diabetes educators, dieticians, nurses and psychologists.[50]

CONCLUSIONS

The current article presents a list of knowledge and behaviors that youth must learn that, at over 600 items, is enormous in its breadth and depth. Simply learning such a substantial amount of information is a challenging task for youth. However, learning these is one thing, whereas helping the child internalize the importance of putting the knowledge into action (i.e., making it a skill) is yet another. Internalization of the importance of the various tasks becomes a key issue prior to transfer of responsibility for control in spite of adequate knowledge of task requirements. Furthermore, when the percentage of <u>adult</u> <u>health professionals</u> adhering to diabetes regimen tasks ranges from 18% to 58% after 4 days,[36] there should be considerable hesitancy to transfer life-long responsibility for control of the diabetes regimen from adults to children who have diabetes. As urged by other researchers, physicians must recommend that adults continue to monitor youth who have been given responsibility for their regimen.[eg,2,50,92-95]

It is hoped that the sheer magnitude of the number of tasks and pieces of knowledge that children must master and implement as illustrated by the task analysis will help physicians be more cognizant of the complexity of what youth with type 1 diabetes and their parents must do. Managing diabetes is a daunting task. The task analysis not only provides physicians with insight into the magnitude of the task, but also provides a resource for guiding physicians in teaching and problem-solving metabolic control. But such a transfer of control, like many other developmental skills, must be approached with sensitivity to the physical and cognitive changes that enable youth at various stages of development to do different things. However, an age-based approach would be inappropriate since youth of the same age and in the same developmental stage may perform and behave very differently. Future research should identify an empirically supported model of self-management that guides developmentally appropriate transfer of control without age-based or task-specific limitations.

When physicians are cognizant of the magnitude of the regimen, physicians become better able to assess for specific adherence problems instead of just global problems; physicians will examine factors that may be interfering with metabolic control that they would not have otherwise assessed (e.g., are youth emotionally overwhelmed rather than oppositional?); and physicians can make developmentally appropriate recommendations for when a youth should be involved versus when a youth should be responsible for specific details of the regimen. This task analysis could even provide physicians a sort of checklist to be used during clinic visits with patients to isolate specific task steps that need attention. Physicians and patients will experience improved management of type 1 diabetes in youth as both become aware of the complex task requirements.

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Table 1. Progression of Transfer of Control Based on Child's Development

Child's Individual Success Is...	**Adults' Roles**	**Adult/Child Behaviors**
IMPOSSIBLE	• complete responsibility • child is only passively involved	Adult does task for child
UNLIKELY	• complete responsibility • high levels of adult involvement • explain the principle/rule of the task in child's terms, but child may not recall it	Adult leads child through the task; child has the physical capabilities to do the task, but the consequences of errors, distraction, or of not knowing how to handle a situation mean limited child performance; adult explains process to the child
POSSIBLE IF SUPERVISED	• adult shares responsibility • moderate levels of adult involvement • child recalls the principle/rule when asked, but needs help in applying it	Adult lets child do the task in the adult's presence while the adult monitors the performance; child completes entire task on own, but adult supervises closely and corrects errors with explanations to teach the child the reasons for behavior
HIGHLY LIKELY	• adult not responsible • inappropriate adult involvement • child recalls and applies the principle/rule appropriately	Adult has witnessed that the child does successfully perform the behavior appropriately under a variety of circumstances without the adult's help, so the child is given complete responsibility for the task

Appendix: Tasks for Managing Type 1 Diabetes

Etiology

- ☐ Knows that nothing s/he did resulted in diabetes
- ☐ States that diabetes may result from viral infections
- ☐ Can explain what diabetes is (functionally)
- ☐ Knows that diabetes is not contagious
- ☐ Can explain the difference between type 1 and type 2 diabetes
- ☐ Can explain the function and need for insulin
- ☐ Can explain the result of a lack of insulin
- ☐ Can explain how diabetes develops
- ☐ Knows that the pancreas produces and secretes insulin
- ☐ Understands that diabetes is a permanent condition

Pharmacology / Insulin

- ☐ Follows an established method for acute insulin adjustment
- ☐ Knows s/he must take insulin injections to provide insulin not made by the pancreas
- ☐ Knows that diabetes is caused by a lack of insulin production
- ☐ Knows that insulin is required every day
- ☐ Knows basic difference between beef, pork, and human insulins
- ☐ Knows the advantages of using human vs. beef/pork insulin
- ☐ Can name the three classes of insulin (short/rapid, intermediate, and long)
- ☐ Can name one insulin of each class of insulins
- ☐ If insulin is not refrigerated it is kept between 59º and 68ºF
- ☐ Extreme temperatures (<36º or >86ºF) are avoided
- ☐ Excess agitation is avoided
- ☐ Knows temperature extremes and agitation can cause loss of usual insulin action
- ☐ Insulin is discarded one month after opening
- ☐ Vials are dated when opened
- ☐ Keeps a spare bottle of each type of insulin used
- ☐ Cold insulin is not injected to reduce local irritation
- ☐ Insulin is not subjected to temperature variations:
  - ☐ Not left in a car
  - ☐ Taken as a carry-on; not checked through in airline baggage
- ☐ Knows signs of deteriorated insulin:
  - ☐ Clear insulins appear cloudy or discolored
  - ☐ Suspended insulins appear clumpy or frosted
- ☐ Discontinues use of deteriorated insulins
- ☐ Knows that absorption rate differs for various injection sites
- ☐ Knows relative rates of absorption for various injection sites (from most to least rapid: abdomen, arm, leg, hip/buttocks)
- ☐ Mixes insulins properly:
  - ☐ The time delay after mixing is standardized
  - ☐ Knows Lente and Ultralente can contaminate Regular insulins
  - ☐ Knows that Lente begins to bind with Regular immediately
  - ☐ Draws up regular insulin prior to suspended insulin
- ☐ Knows that normalization of BG can be achieved only via a small amount of insulin working continuously (e.g., Lente/Ultralente) with boluses (e.g., Humalog/Regular) at meals
- ☐ Does not change insulin species without physician consult
- ☐ Knows that insulin effectiveness varies as a function of exercise, stress, food absorption rates, insulin mix, and hormonal changes
- ☐ Knows what kinds of insulins s/he takes
- ☐ Knows the physical characteristics of the various types of insulin
- ☐ Knows the functional characteristics[a] of the various types of insulin
- ☐ Knows that injections must be given at about the same time daily
- ☐ Understands why insulin should be given at same times daily
- ☐ Knows where insulin may be purchased
- ☐ Purchases insulin and syringes
- ☐ Knows that at puberty, insulin requirements may change
- ☐ Knows pre-pubertal children usually require .6-.9 U of insulin /kg/day
- ☐ Knows that pubertal children may require up to 1.5 U/kg/day
- ☐ Knows that post-pubertal patients usually require <1 U/kg/day
- ☐ Knows that too much insulin can lead to unstable control
- ☐ Knows that doses above 1 U/kg/day can cause rebound hyperglycemia and weight gain

Insulin Technique

- ☐ States the prescribed amount of each insulin type prescribed
- ☐ Chooses the correct insulin bottle
- ☐ Removes needle cover properly
- ☐ Turns insulin bottle upside down with the syringe inserted
- ☐ Pulls plunger back to draw insulin
- ☐ Draws insulin to the correct unit mark
- ☐ Pushes plunger all the way down when injecting (gives full dose)
- ☐ Cleans the injection site after injection
- ☐ Records amount of insulin dose on record sheet
- ☐ Organizes all necessary materials prior to injection (limits errors)
- ☐ Cleans hands prior to injection
- ☐ Cleans the injection site prior to injection
- ☐ Waits for topical alcohol, if used on site, to dry before injecting
- ☐ Cleans the top of the insulin vial with 70% isopropyl alcohol
- ☐ Gently rolls (does not shake) all but short-acting insulins before drawing up insulin

- ☐ Injects air equal to the insulin dose into the vial (not the insulin) prior to drawing up insulin to avoid creating a vacuum
- ☐ For mixed doses, injects a volume of air into both vials before drawing up any insulin
- ☐ Short-acting insulins are drawn before intermediate-/long-acting
- ☐ Syringe is checked for bubbles after dose is drawn
- ☐ Flicks syringe until bubbles escape
- ☐ An appropriate injection site is selected:
  - ☐ Upper arm
  - ☐ Anterior and lateral aspects of the thigh
  - ☐ Buttocks
  - ☐ Abdomen (but not within 2 in. of the navel)
- ☐ Knows why it is important to rotate injection sites
- ☐ Injection sites are rotated to prevent local irritation
- ☐ Injection sites are rotated within 1 area type for consistent absorption
- ☐ Avoids injections into body areas likely to be exercised
- ☐ Insulin is injected subcutaneously (not intramuscular/venous)
- ☐ An appropriate injection angle is used (45º angle for a child or thin person, else 90º)
- ☐ A fold of skin is grasped or pinched up for injection
- ☐ Keeps muscles in injection area relaxed while injecting
- ☐ Penetrates the skin quickly
- ☐ Does not change the direction of the needle during insertion/withdrawal
- ☐ Checks injection site for blood or fluid after injection
- ☐ Increases BG monitoring if site is wet after injection
- ☐ Safely handles syringes
- ☐ Safely disposes of used syringes
- ☐ Never shares a used syringe with another person
- ☐ Alcohol is not used directly on the needle (it removes the silicon coating)
- ☐ Increases BG monitoring if length of needle is changed

Blood Glucose (BG) and Ketone Monitoring

- ☐ Knows schedule for testing BG
- ☐ Knows that ketones come from the breakdown of fat for energy
- ☐ Knows that ketones result when the body can't use glucose for energy
- ☐ Knows that ketones may indicate too little insulin
- ☐ Explains how to check for ketones
- ☐ Demonstrates how to test urine for ketones
- ☐ Explains the steps to check BG using his/her glucose system
- ☐ Demonstrates the fingerstick for BG monitoring
- ☐ Demonstrates how to record results of BG test
- ☐ Knows which end of BG strip to insert into meter
- ☐ Does not touch strip on electrical contacts
- ☐ Cleans target lancet site before obtaining drop of blood
- ☐ Cleans target site after blood is used—prevents infection
- ☐ Uses a new lancet for each blood draw
- ☐ Disposes of lancet safely
- ☐ Re-seals bottle of test strips to prevent extended exposure
- ☐ Disposes of used test strip safely/hygienically
- ☐ Remembers to take BG monitor with him/her when leaving home
- ☐ Remembers to take enough strips with him/her when leaving home
- ☐ Remembers to take enough lancets with him/her when leaving hm
- ☐ Uses an electronic glucose monitor
- ☐ Uses BG trends to adjust insulin dosage
- ☐ Knows when to give rapid acting insulin supplements
- ☐ Indicates quantity and frequency of insulin supplements when needed
- ☐ Uses results to adjust caloric intake
- ☐ Uses results to adjust physical activity
- ☐ Uses results to learn about individual response to food items
- ☐ Uses results to learn about how stress affects BG
- ☐ Uses results to diagnose and treat hypoglycemia
- ☐ Monitors every 4-6 hours for glucose and ketones when sick
- ☐ Increases monitoring when traveling across time zones
- ☐ Monitors to determine basal and bolus doses if on an insulin pump
- ☐ Uses results to evaluate the effect of self-management changes
- ☐ Obtains a drop of blood sufficient for accurate result
- ☐ Maintains temperature stability of meter and strips (<86º F)
- ☐ Calibrates the meter with each new lot number (if required)
- ☐ Does not use urine tests for glucose monitoring
- ☐ Records results in a log (even if the monitor has memory)
- ☐ Appropriately tests for dawn phenomenon (takes BG at 3-4 a.m.)
- ☐ Monitors at least before meals and at bedtime
- ☐ Monitors more if there has been hypo-/hyperglycemia/ketosis
- ☐ Checks for ketones when BG is consistently >240 mg/dL
- ☐ Knows target BG levels:
  - ☐ Children ≥ 6 yrs: 80-120 mg/dL at fasting
  - ☐ Children ≥ 6 yrs: 80-180 mg/dL at other times of day
  - ☐ Children < 6 yrs: 90-130 mg/dL at fasting
  - ☐ Children < 6 yrs: 90-200 mg/dL at other times of the day
- ☐ Identifies things that influence BG levels (e.g., exercise, stress, etc.)
- ☐ Can define glycosylated hemoglobin or hemoglobin A_{1c}
- ☐ Knows that A_{1c} measures identify average BG levels during the last 1-3 months)
- ☐ Can identify hemoglobin results indicating good control

- ☐ Knows that a good A_{1c} will be deceptive if there have been multiple lows when there have also been many highs
- ☐ Knows that BG levels can vary even when there is no deviation from the regimen

Diet

- ☐ Knows that all CHO becomes sugar when digested
- ☐ Knows that sugar is CHO
- ☐ Knows that generally, simple CHOs are absorbed rapidly
- ☐ Knows that generally, simple CHOs produce rapid BG elevations
- ☐ Can name several foods with simple CHOs
- ☐ States that generally, complex CHOs are absorbed more slowly than simple CHOs
- ☐ Can name several foods with complex CHOs
- ☐ Knows that there are exceptions to the way simple and complex CHOs affect BG
- ☐ Knows that exceptions are related to a food's Glycemic Index (GI) and Glycemic Load (GL)
- ☐ Knows that foods with a low GI number raise BG slowly and foods with a high GI raise BG rapidly
- ☐ Can name at least one simple carbohydrate with a low GI
- ☐ Can name at least one complex carbohydrate with a high GI
- ☐ Can define GL in relation to BG
- ☐ Demonstrates the ability to interpret labels on sugar-free products appropriately
- ☐ Describes how sugar gets into the body
- ☐ States that blood sugar levels are caused by food for the most part
- ☐ States that some sugar can be made from protein
- ☐ Knows that everyone has glucose in their blood
- ☐ Eats at consistent times
- ☐ Knows that skipping a meal or snack can significantly affect BG
- ☐ Meals are synchronized with time-actions of insulin
- ☐ Knows that about the same amount and types of food must be eaten from day to day
- ☐ Knows that food from one meal cannot be substituted at another
- ☐ Knows CHO, protein, and fat must be balanced for good health
- ☐ Gets 55-60% (adults: 45-55%)[b] of calories from CHO
- ☐ Limits concentrated sweets[c] (i.e., sucrose), including sugar-free products, because they do not contain an appropriate balance of CHO, protein, fat, nutrients, and fiber
- ☐ Gets <30% of daily calories from fat
- ☐ Gets <7% of daily calories from saturated fat
- ☐ Gets <200 mg of cholesterol daily
- ☐ Knows that excessive fat can cause significant health problems
- ☐ Gets 12-15% of calories from protein (adults: .8-1.2g/kg)
- ☐ Can evaluate food labels for nutritive (caloric) sweeteners
- ☐ Gets <3000 mg of sodium per day (1000 mg/1000 kcal)
- ☐ Selects appropriate foods from a menu
- ☐ Reads labels on packaged foods
- ☐ Knows that diet is an essential element of diabetes control
- ☐ Follows precautions regarding alcohol use:
  - ☐ Eats before[d] drinking any alcohol
  - ☐ ≤2 alcoholic equivalents[e] used 1-2 times / wk (ideally, none)
  - ☐ Food is not omitted[f] when alcohol is consumed
  - ☐ Knows that fruit juice or mixers with sugar added to alcohol can significantly affect BG
  - ☐ Knows that drinking alcohol that contains carbohydrate can significantly affect BG
  - ☐ Knows that drinking may cause him/her to forget shots, eat too much, etc., and takes precautions against this
  - ☐ Eats bedtime snack even if BG is high after alcohol consumption
- ☐ Follows guidelines for handling nausea and vomiting:
  - ☐ 15g of carbohydrate consumed over 1-2 hours in small quantities or, 50g consumed every 3-4 hours to prevent starvation ketosis
  - ☐ Drinks small sips of fluids every hour or so
  - ☐ Replaces electrolytes via small amounts of salty foods/liquids
  - ☐ Sips 15g of CHO over 1-2 hrs if foods/liquid cannot be tolerated
- ☐ Follows a meal plan (which itself will have multiple tasks)
- ☐ If patient is on an exchange system:
  - ☐ Knows that a Starch/Bread exchange contains 15 grams of CHO
  - ☐ Knows that a Fruit exchange contains 15 grams of CHO
  - ☐ Knows that a Milk exchange contains 12 grams of CHO
- ☐ Follows caloric guidelines for age/weight/activity
- ☐ Does not deviate >1hr. from scheduled snacks
- ☐ Sees a registered dietitian every 3-6 mos. (6-12 mos. for adult)
- ☐ Knows high-fiber diets improve CHO metabolism, lowers total cholesterol and LDL cholesterol
- ☐ Gets 35-50g of fiber/day (25 g/1000 kcal, but not >50g)
- ☐ Eats at least 3 regular meals, a bedtime snack, and one or more between-meal snacks (may differ if on intensive insulin therapy)
- ☐ Knows that children/teens may need 1-2 snacks to maintain growth

Exercise

- ☐ Knows that people with diabetes are not restricted in amount of exercise
- ☐ Knows how much CHO is needed acutely per hour of exercise (generally is 10-15g / hr)
- ☐ Decreases insulin when appropriate
- ☐ Increases daily food intake when necessary
- ☐ Eats CHO after exercise to avoid post-exercise hypoglycemia
- ☐ Knows how long glucose will decline after exercise (can continue to decline 12-24 hrs)

☐ Avoids insulin injections close in time to exercise
☐ Monitors glucose before, during, and after exercise
☐ Adjusts insulin/eats considering relevant factors:
  ☐ The time of exercise in relation to type and quantity of insulin
  ☐ Body part exercised relative to location of insulin injection and time since injection
  ☐ Type, intensity, and duration of exercise
  ☐ The previous meal time and type
  ☐ Pre-exercise blood glucose level
☐ Adjusts insulin/eats appropriate[g] quantities
☐ Knows that exercise usually requires additional food intake
☐ Waits 60-90 minutes after a meal to exercise
☐ Avoids exercising during insulin's peak effect
☐ Exercises only if BG is between 100-200 mg/dL and no ketones
☐ Carries a fast-acting carbohydrate
☐ Wears ID/medic alert at all times, but especially while exercising
☐ Exercises with someone familiar with his/her diabetes
☐ Has properly fitting and protective exercise shoes
☐ Exercise is stopped when feeling faint
☐ Exercise is stopped when pain is experienced
☐ Exercise is stopped when unusually short of breath
☐ Exercise is stopped when hypoglycemic
☐ Knows that low-intensity exercise (<50% of maximum heart-rate reserve) has less effect on BG than high-intensity exercise
☐ Can calculate maximum heart-rate (HR) reserve and target HR[h]
☐ Works with health professionals to develop an individualized exercise program [for diabetics with no complications present]
☐ Works with health professionals to develop an exercise program in light of concurrent diabetic complications
☐ Knows that regular exercise is an important part of diabetes control
☐ Consistently participates in an appropriate exercise program
☐ Knows that exercise increases sensitivity to insulin
☐ Knows that exercise increases glucose utilization
☐ Can indicate diabetes-specific benefits[i] of exercise
☐ Knows that glucose production by the liver is inhibited by exercise
☐ Knows exercise depletes glycogen stores which must be replenished and can lead to prolonged glucose-lowering effects
☐ Uses proper footwear
☐ Avoids exercising in extreme heat or cold
☐ Inspects feet after exercising
☐ Avoids exercise during periods of poor metabolism
☐ Identifies an appropriate pre-exercise snack
☐ Does not exercise if ketones are positive
☐ Eats 10-15g (or individualized amount) of rapid-acting CHO every 30-60 minutes of exercise
☐ Knows that exercising when BG is already high can increase BG even more
☐ Reduces insulin dose for respective period by about 20% after strenuous activity lasting more than 45-60 minutes
☐ Knows that high BG after exercise may be temporary due to adrenaline and so waits 60 minutes before bolusing

Hypoglycemia

☐ Defines hypoglycemia as low blood sugar
☐ Tests glucose before, during, and after treatment of hypoglycemia
☐ Knows that treating hypoglycemic symptoms will terminate them
☐ Knows that hypoglycemia gets worse if not treated
☐ Knows that treatment of hypoglycemia consists of eating sugar
☐ Begins treating with 10-15g of CHO (5-10 for younger children)
☐ Knows that it takes 10-15 minutes for treatment to terminate symptoms of hypoglycemia
☐ Glucose is tested 15 minutes after treating
☐ Additional 15g CHO taken after 10-15 minutes if symptomatic or glucose <70 mg/dL
☐ Does not treat hypoglycemia with chocolate or ice cream (fat reduces rate of CHO availability)
☐ The scheduled snack or meal is eaten following treatment
☐ The food used to treat is in addition to regular meal plan
☐ Knows that symptoms are usually felt when BG is low
☐ Knows that BG<70 mg/dL indicates impending hypoglycemia
☐ Can describe typical[j] symptoms
☐ Can describe idiosyncratic symptoms
☐ Recognizes their own hypoglycemia
☐ Knows that hypoglycemic symptoms can occur with rapid BG declines even if measured BG is greater than 70 mg/dL
☐ Treats symptoms of hypoglycemia even if BG cannot be tested
☐ Knows the typical causes of hypoglycemia, such as:
  ☐ Excessive insulin
  ☐ Skipped or inadequate meals
  ☐ Immediate effects of exercise
  ☐ Long-term effects of exercise
  ☐ Ingestion of ethanol without food
  ☐ Onset of monthly menstrual cycle
  ☐ Autonomic neuropathy leading to delayed gastric emptying
☐ Decreases insulin or increases food intake appropriately in response to patterned hypoglycemia
☐ Notifies health professional following severe (e.g, unconsciousness) hypoglycemic episodes
☐ Knows insulin needs are lower between midnight and 3 am
☐ Knows that nighttime hypoglycemia can occur without waking the person
☐ Checks 3 am BG at least once a week
☐ Checks 3 am BG following a day of unusual activity
☐ Checks 3 am BG following a day of unusual food consumption

- ☐ Checks 3 am BG when insulin doses are being adjusted
- ☐ Always measures bedtime BG to prevent nocturnal hypoglycemia
- ☐ Has a bedtime protein+CHO snack if bedtime BG<120 mg/dL
- ☐ Moves dinner intermediate-/long-acting insulin to bedtime if a reduction in short-term dose at dinner is made to prevent nocturnal hypoglycemia and if this results in fasting hyperglycemia
- ☐ Avoids delaying a meal more than 30 to 60 minutes
- ☐ Carries a source (or sources) of CHO (10g-15g) at all times
- ☐ Knows how to inform family and friends how to treat hypoglycemia
- ☐ Knows what glucagon is
- ☐ Glucagon is kept available
- ☐ Knows glucagon takes 10-15 minutes to work
- ☐ Makes sure family/friends know when and how to administer glucagon
- ☐ Adjusts treatment plan in response to repeated daily hypoglycemia
- ☐ Knows that insulin may need to be reduced if weight is lost
- ☐ Knows small ketones in the morning may indicate nocturnal hypoglycemia
- ☐ Treats hypoglycemia as soon as symptoms are noticed
- ☐ Knows hypoglycemia can lead to unconsciousness or seizure
- ☐ Takes safety precautions when experiencing hypoglycemia (e.g., stops driving, etc.)
- ☐ Knows glucagon is available only by prescription
- ☐ Keeps glucagon at home and at work/school
- ☐ Has informed family/friends/co-worker/teacher:
  - ☐ To give glucagon if s/he passes out
  - ☐ To call for emergency help
  - ☐ Not to give him/her insulin
  - ☐ Not to give him/her food or fluids
  - ☐ Not to put their hands in his/her mouth
- ☐ Knows that things other than hypoglycemia can cause symptoms (anxiety, fatigue, etc.)
- ☐ Knows types of food/drinks that effectively treat hypoglycemia
- ☐ Knows that there is a possibility for a rebound hyperglycemia after hypoglycemia
- ☐ Knows that the rebound may be due to the action of counter-regulatory hormones
- ☐ Knows counter-regulatory hormones may also produce ketonuria
- ☐ Knows rebound can occur without hypoglycemic symptoms
- ☐ Knows hypoglycemia is most likely when insulin effects are peaking
- ☐ Knows that one incident of severe hypoglycemia is frequently followed by another hypoglycemia incident
- ☐ Knows how to decrease the potential of a second hypoglycemic incident following an earlier hypoglycemic incident

Hyperglycemia

- ☐ Knows typical[K] symptoms
- ☐ Knows idiosyncratic symptoms
- ☐ Discusses appropriate treatment of hyperglycemia with doctor
- ☐ Applies prescribed treatment when hyperglycemic
- ☐ Knows that some types of neuropathy are related to the duration and severity of hyperglycemia

Ketoacidosis (KA)

- ☐ Knows that KA means dangerously high levels of ketones
- ☐ Knows that KA means the body is burning fat (instead of glucose) for energy and this results in ketones as a by-product
- ☐ Knows ketones are acids that build up in the blood
- ☐ Knows that ketones are found in the urine if there is an insulin deficiency
- ☐ Knows ketones poison the body
- ☐ Knows KA can lead to coma and death (i.e., is life-threatening)
- ☐ Knows ketones can indicate the onset or presence of illness
- ☐ Knows ketones can indicate the diabetes is “out of control”
- ☐ Knows KA usually results in hospitalization
- ☐ Knows KA usually develops slowly
- ☐ Knows KA can develop within a few hours when vomiting occurs
- ☐ Knows initial symptoms of KA:
  - ☐ Thirst and/or a very dry mouth
  - ☐ Excessive urination
  - ☐ High BG levels
  - ☐ “Moderate”[l] quantities of ketones as measured by urine samples
- ☐ Knows subsequent symptoms of KA:
  - ☐ Constantly feeling tired
  - ☐ Dry or flushed skin
  - ☐ Nausea, vomiting, or abdominal pain
  - ☐ Difficulty breathing
  - ☐ Fruity odor on breath
  - ☐ Difficulty concentrating or confusion
- ☐ Calls physician or goes to ER immediately if any of the symptoms are present
- ☐ Has test strips available to test for ketones
- ☐ Tests for ketones every 4-6 hours when ill
- ☐ Tests for ketones every 4-6 hours when BG >240
- ☐ Tests for ketones when any symptoms of KA are present (e.g., nausea, vomiting, abdominal pain)
- ☐ Knows ketones can result from lack of insulin, lack of food, or an untreated insulin reaction (e.g., nocturnal hypoglycemia)
- ☐ Knows to drink lots of water when ketones are present

Illness/Stress

- ☐ Knows that illness/stress can raise BG levels
- ☐ Knows that illness/stress increases chance of KA
- ☐ Knows that during illness insulin needs may increase in spite of decreased food intake
- ☐ Knows that insulin action is diminished during illness/stress

- ☐ Knows that glucose is released by the liver during illness/stress
- ☐ Drinks ≥ 8 oz. of water/hr while awake to prevent dehydration
- ☐ Avoids caffeinated drinks (which are diuretics)
- ☐ Increases BG monitoring frequency during illness/stress
- ☐ Knows that symptoms of illness/stress can mask and/or mimic usual symptoms of hypo-/hyperglycemia
- ☐ Is able to test ketones
- ☐ Tests ketones every 4-6 hours during illness/stress
- ☐ Checks BG before adjusting insulin dose
- ☐ Knows that insulin must be given even when unable to eat
- ☐ When unable to eat:
  - ☐ Gives full dose of intermediate/long-acting insulin
  - ☐ Supplements with 10% of routine dose of short-acting insulin
  - ☐ Supplements with 20% if BG>300 mg/dL and ketones are large
- ☐ Knows that supplements of short-acting insulin may be needed
- ☐ Knows or inquires about the effects of medications on BG
- ☐ Uses sugar-free over-the-counter medications (OTCs) if possible
- ☐ Increases BG monitoring when using OTCs that advise against use by persons with diabetes and calls health professional if necessary
- ☐ Knows whom to call in case of illness
- ☐ Calls a health professional if:
  - ☐ Vomiting occurs more than once
  - ☐ Diarrhea lasts >24 hrs or occurs >5 times
  - ☐ Breathing is difficult
  - ☐ BG>300 mg/dL on two consecutive measurements
  - ☐ Urine ketones are moderate or large
- ☐ Has developed a plan of action with his/her physician:
  - ☐ When to call the physician
  - ☐ When to increase BG and ketone monitoring
  - ☐ Types of foods and fluids to take during illness
  - ☐ How to adjust medication during illness
- ☐ Calls physician if:
  - ☐ The illness does not improve after 1-2 days
  - ☐ Diarrhea or vomiting persists for >6 hours
  - ☐ Ketones in urine measure moderate to large
  - ☐ Abnormal sleepiness
  - ☐ Any doubt about what to do for the illness
  - ☐ Any symptoms of KA
- ☐ Checks with physician or pharmacist regarding the effect of a drug on diabetes control
- ☐ Participates in a regular exercise program to combat stress
- ☐ Knows idiosyncratic response[m] to stress
- ☐ Uses appropriate stress management techniques

Traveling

- ☐ Takes appropriate[n] supplies and phone numbers
- ☐ Appropriately stores and keeps accessible supplies during travel
- ☐ Keeps meal and snack times as consistent as possible
- ☐ Monitors glucose before driving
- ☐ Keeps extra source of carbohydrate in car to treat hypoglycemia
- ☐ Prevents freezing of insulin, meters, and strips

Continuous Subcutaneous Insulin Infusion (CSII; Insulin Pump)

- ☐ Knows primary purpose for CSII is improved control and reduced diabetic complications
- ☐ Has realistic expectations for CSII
- ☐ Knows major risks of CSII (ketoacidosis, hypoglycemia, site infection)
- ☐ Counts CHO when available on food packages
- ☐ Counts CHO when available from restaurant printed materials
- ☐ Estimates CHO as accurately as possible when info not available
- ☐ Knows that "basal" refers to the amount of 24-hr continuously delivered insulin in units per hr (usually .4 - 1.6)
- ☐ Knows that "bolus" refers to a rapidly delivered dose of insulin
- ☐ Knows that 45-60% of total amount of insulin needed per day is usually delivered as basal
- ☐ Knows that 40-55% of total amount of insulin needed per day is usually delivered as boluses to cover meals (CHO)
- ☐ Knows that basal is too high if BG drops when a meal is skipped
- ☐ Knows that basal is too high if BG is often low early A.M. or before breakfast
- ☐ Knows that basal is too high if BG is repeatedly low during day
- ☐ Knows that basal is too low if BG rises when a meal is skipped
- ☐ Knows that basal is too low when BG is repeatedly high during day
- ☐ Knows to change basal rates in small increments well before (~6 hrs) the time when the problem BG is noticed
- ☐ Knows to use different basal rates on weekends if weekend activities are quite different
- ☐ Tests BG at least 4-6 times per day (ideally, pre- and post-prandial, before bed, and at night)
- ☐ Tests BG before driving
- ☐ Records BG readings
- ☐ Records basals
- ☐ Records boluses
- ☐ Records hypoglycemia
- ☐ Records hypoglycemia treatments
- ☐ Records carbohydrate intake
- ☐ Records exercise duration and intensity
- ☐ Records time and date for each item recorded (BG, basal, bolus…)
- ☐ Matches basals and boluses to insulin need by problem-solving blood sugar patterns
- ☐ Knows how to program and change basals and boluses
- ☐ Overnight basal is stable (bedtime BG 80-120 mg/dl with normal morning BG)

- ☐ Daytime basal is stable (can skip a meal if preprandial BG 100-120 mg/dl without BG dropping >30 over 5 hours)
- ☐ Accurately boluses for CHO (if pre-prandial BG is normal, can bolus insulin so BG is normal 4 hrs later)
- ☐ High BG bolus (can bolus insulin to normalize BG 4 hrs later)
- ☐ Prevents "stacking" (if 2 boluses ≤ 3.5 hrs apart, determines unused insulin from 1st bolus; typically 30% of bolus is used / hr)
- ☐ Recognizes hypoglycemic reactions
- ☐ Handles hypoglycemic reactions without BG rising ≥ 150 mg/dl
- ☐ Knows likely causes of hypoglycemia with CSII
- ☐ Infrequent SMBG
- ☐ Improper timing of bolus
- ☐ Using too large a bolus or too many (e.g., "stacking")
- ☐ Too few CHO in meal
- ☐ Increased activity
- ☐ Has non-expired Glucagon emergency kit at home for use
- ☐ Home support person is trained to use Glucagon
- ☐ Has non-expired Glucagon emergency kit at school for use
- ☐ School support person is trained to use Glucagon
- ☐ Can keep BG between 70-150 mg/dl when exercising
- ☐ Can insert/change pump batteries
- ☐ Always has spare batteries available
- ☐ Programs pump to deliver correct basal rate
- ☐ Uses the pump to deliver correct bolus
- ☐ Inserts insulin reservoir into pump
- ☐ Attaches infusion set to reservoir
- ☐ Inserts infusion set needle/catheter at insertion site
- ☐ Identifies pump alarms
- ☐ Knows how to stop or suspend pump
- ☐ Knows how to review pump memory for basals, boluses, alarms, etc.
- ☐ Knows how to wear the pump
- ☐ Can analyze BG patterns
- ☐ Knows how to correct problematic BG patterns
- ☐ Does not skip or delay a meal after a bolus of rapid acting insulin
- ☐ Does not suspend pump to treat low BGs
- ☐ If BG ≥ 300 mg/dl, takes bolus by syringe
- ☐ Has set schedule for days to change infusion site
- ☐ Changes infusion site within 72 hrs
- ☐ Ensures O-rings (where present) are lubricated regularly
- ☐ Can transfer insulin into reservoir
- ☐ Eliminates bubbles from reservoir
- ☐ Can detach reservoir needle and replace it with infusion set hub
- ☐ Prevents leaks from hub by firmly tightening hub to reservoir
- ☐ Primes infusion line with insulin before inserting into pump, or, uses pump to prime infusion line
- ☐ Uses pump bolus operation to fill infusion set to tip
- ☐ Washes hands prior to preparing infusion site
- ☐ Does not touch parts that will indirectly or directly contact infusion site
- ☐ Does not breathe on or blow on parts that will indirectly or directly contact infusion site
- ☐ Disinfects 2-inch diameter area of skin around infusion site
- ☐ Allows disinfected infusion area to dry before proceeding
- ☐ Places medical adhesive on infusion site
- ☐ Positions infusion set needle parallel to beltline but not underneath belt
- ☐ Properly boluses if using Teflon infusion set
- ☐ Loops infusion line and tapes it to skin 1-inch from infusion site
- ☐ Checks infusion site daily
- ☐ Changes infusion site immediately when red, swollen or bleeding
- ☐ Never primes infusion set when it is still attached to body
- ☐ Never attempts to unclog infusion line when it is attached to body
- ☐ Changes infusion sets in mornings, not evenings
- ☐ Knows his/her insulin to CHO ratio (ICR) for CHO counting / bolusing
- ☐ Measures servings of foods eaten carefully (measuring cups, scales, etc.) to accurately count CHO
- ☐ Knows by how many mg/dl 1g of CHO raises his/her BG
- ☐ Knows by how many mg/dl 1U of insulin lowers his/her BG
- ☐ Knows by how many mg/dl a certain degree and length of exercise lowers his/her BG
- ☐ Has contact information for 24-hour help with pump
- ☐ Knows that insulin reactions are less dramatic on CSII and requires more frequent BG monitoring
- ☐ Handles pump properly when bathing (detaches, hangs, etc.)
- ☐ Handles pump properly when sleeping (free under pillow, clamped to PJs, etc.)
- ☐ Does not expose pump to heat (e.g., hot tubs or saunas)
- ☐ Knows how to detach pump during exercise or showering, etc.
- ☐ Prevents water exposure if pump is not waterproof
- ☐ Has preparations in place in case of pump problems
- ☐ Knows glycemic index information for foods
- ☐ Can adjust bolus for glycemic index of foods
- ☐ Can insert infusion set subcutaneously
- ☐ Determines his/her total amount of insulin needed per day
- ☐ Adjusts her total amount of insulin needed per day for premenstrual rises in blood sugars
- ☐ Adjusts basal when stress leads to increased BG
- ☐ Adjusts basal when illness results in increased BG
- ☐ Establishes stable basal rates before adjusting bolus ratios
- ☐ Knows that kids often need additional basal in early A.M. when surges of growth hormone can occur
- ☐ Ensures school has backup necessities (batteries, infusion set, reservoir, insulin, etc.)

- ☐ Knows how to troubleshoot pump issues for high BGs:
  - ☐ Ensures insertion set is properly placed under skin
  - ☐ Ensures insertion site is free of physical problems (scarring, etc.)
  - ☐ Considers use of a different site that provides better absorption
  - ☐ Ensures that cannula is not crimped
  - ☐ Ensures line is free of blood
  - ☐ Ensures line is free of air
  - ☐ Ensures line is not clogged:
    - ☐ Removes insertion set from body
    - ☐ Has pump deliver a ~5U bolus
    - ☐ Insulin should come out of infusion set needle
  - ☐ Ensures infusion set is securely connected to pump
  - ☐ Ensures infusion line is not damaged/does not leak
  - ☐ Ensures hub is not loose
  - ☐ Ensures O-ring does not have a leak
  - ☐ Ensures basal settings are correct
  - ☐ Ensures bolus dose was correct
  - ☐ Ensures bolus was given at correct time
  - ☐ Ensures pump is not in suspend mode
  - ☐ Ensures that reservoir has insulin
  - ☐ Ensures potency of insulin (typically by discarding current insulin and replacing with new insulin)
- ☐ Knows circumstances leading to "insulin tunneling" (insulin leaks out around skin at insertion set site)
- ☐ Acts on pump alarms by troubleshooting or planning
- ☐ Knows what foods or products are rapid acting CHOs
- ☐ Always carries rapid acting CHOs
- ☐ Knows what a square-wave bolus is vs. dual-wave bolus
- ☐ Knows when to use square-wave vs. dual-wave bolus

Complications

- ☐ Knows possible acute and long-term complications of diabetes mismanagement:
  - ☐ Hypoglycemia
  - ☐ Ketoacidosis
  - ☐ Hyperglycemia
- ☐ Knows that most acute complications can be avoided with proper care
- ☐ Knows potential complications of diabetes:
  - ☐ Hypoglycemia
  - ☐ Hyperglycemia
  - ☐ Periodontal disease (gum infection):
    - ☐ Knows diabetics are at increased risk for gum disease
    - ☐ Brushes teeth at least twice/day
    - ☐ Uses dental floss once a day to remove bacteria from between teeth
    - ☐ Brushes where the teeth meet the gums
    - ☐ Sees the dentist every 6 months
    - ☐ Sees the dentist if gums bleed while eating or brushing teeth
  - ☐ Diabetic KA
  - ☐ Hypertension:
    - ☐ Arterial blockage can cause impotence
  - ☐ Retinopathy (eye disease):
    - ☐ Knows that nearly all patients with diabetes develop some degree of retinopathy after 20 years
    - ☐ Knows that hyperglycemia is associated with retinopathy
    - ☐ Knows that hypertension is associated with retinopathy
    - ☐ Knows vision-threatening retinopathy may be asymptomatic
    - ☐ Knows that laser photocoagulation therapy can prevent vision loss in many patients with retinopathy
    - ☐ Knows that many eye problems are minor and easily treated
    - ☐ Knows that some eye problems are serious and may cause blindness
    - ☐ Knows diabetes is the leading cause of blindness for adults in U.S.
    - ☐ Knows 80% of diabetics will develop at least some background retinopathy after 15 years of diabetes
    - ☐ Receives a comprehensive ophthalmologic exam once/yr after having diabetes for 5 years
    - ☐ Reports any change in vision to the physician
  - ☐ Nephropathy (kidney disease):
    - ☐ Knows that high BG levels may cause blood vessel changes over time that prevent the Kidneys from filtering out waste
    - ☐ Knows that swelling of feet and ankles, feeling tired, and pale skin can indicate kidney damage
    - ☐ Knows that kidney damage may necessitate hemodialysis
    - ☐ Knows that high blood pressure and frequent urinary tract infections can affect kidney function
    - ☐ Occurs in about 30% of people with diabetes
    - ☐ Occurs, on average, 20 years after diagnosis
    - ☐ Knows symptoms are not readily detectable by the patient
  - ☐ Cardiovascular disease
  - ☐ Neuropathy:
    - ☐ Can lead to impotence
    - ☐ Knows that peripheral neuropathy is the most common long-term complication of diabetes
    - ☐ Knows that some types of neuropathy are related to the duration and severity of hyperglycemia
    - ☐ Knows 50% of diabetics will develop some sort of neuropathy
  - ☐ Foot problems:
    - ☐ Knows foot problems are a major cause of morbidity, mortality, and disability in diabetics
    - ☐ Knows problems in the presence of neuropathy/ischemia can result in lower-extremity amputations
    - ☐ Knows daily foot inspection is preventative of amputations
    - ☐ Knows patients with neuropathy are at high risk for foot ulcers
    - ☐ Knows patients with vascular disease are at high risk for foot ulcers
    - ☐ Knows hyperglycemia can increase risk of foot problems
    - ☐ Knows that foot problems can develop quickly

- ☐ Knows symptoms of poor circulation related to foot problems:
  - ☐ Cold feet
  - ☐ Leg cramps
  - ☐ Shiny or dry skin
  - ☐ Loss of hair on the toes, feet, or legs
  - ☐ Slow healing of foot and leg injuries
- ☐ Knows symptoms of nerve damage related to foot problems:
  - ☐ Pain, numbness, burning, and/or tingling in the legs/feet
  - ☐ Very little feeling in the feet
- ☐ Knows feet may become very dry and skin may crack
- ☐ Applies lotion to feet after bathing
- ☐ Does not apply lotion between toes
- ☐ Has physician examine feet at each visit
- ☐ Washes feet every day with mild soap
- ☐ Never uses very hot water to wash feet
- ☐ Dries feet carefully, especially between the toes
- ☐ Checks feet and between toes every day
- ☐ Reports foot infections to physician
- ☐ Checks inside shoes for pebbles/objects before putting them on
- ☐ Checks water temperature with finger/elbow (not feet) before bathing
- ☐ Avoids hot water bottles, heating pads, or electric blankets which can cause burns without feeling them if neuropathy is present
- ☐ Never walks barefoot
- ☐ Has physician cut corns and calluses (does not self-treat)
- ☐ Wears shoes that fit and are comfortable
- ☐ Changes socks/nylons every day and wears socks/nylons that are even and smooth and keeps them from wrinkling while wearing
- ☐ Does not soak feet
- ☐ Toenails are cut slightly curved to the contour of the toe
- ☐ Does not use chemicals on feet (e.g., to remove corns, etc.)
- ☐ Maintains proper circulation (i.e., avoids sitting with legs crossed, tight garments, etc.)
- ☐ Assesses feet for redness, swelling, cuts, blisters, calluses, dryness, cracks, corns, and any change in appearance
- ☐ Seeks care within 48 hours for even “small” problems

☐ Neurogenic bladder (damage to bladder nerve fibers):
- ☐ Diminished urination frequency
- ☐ Difficult/incomplete bladder emptying
- ☐ Frequent urinary infections

☐ Sexual dysfunction (due to nerve damage):
- ☐ Males: 75% experience difficulties
- ☐ Males: retrograde ejaculation
- ☐ Males: impotence; loss of erectile capacity
- ☐ Females: reduction in arousal
- ☐ Females: diminished vaginal lubrication
- ☐ Females: decreased frequency of orgasm

- ☐ Gastroparesis (due to nerve damage):
  - ☐ Early satiety
  - ☐ Feeling full after meals
  - ☐ Heartburn, reflux
  - ☐ Reduced appetite
  - ☐ Hypoglycemia after meals (delayed stomach-emptying)
- ☐ Intestinal disorders (due to nerve damage):
  - ☐ Constipation (in up to 60% of diabetics)
  - ☐ Nocturnal diarrhea
  - ☐ Incontinence
- ☐ Cardiovascular disorders (due to nerve damage):
  - ☐ Postural hypotension (systolic drop when moving to stand)
  - ☐ Painless heart attack and sudden death
  - ☐ Fixed heart rate
- ☐ Pupillary (abnormalities due to nerve damage):
  - ☐ Reduced responsiveness to light
  - ☐ Decreased pupil size
- ☐ Coronary artery disease:
  - ☐ Knows this is the greatest cause of mortality in diabetes
  - ☐ Mortality is 2-4 (possibly 8) times that of non-diabetic populations
- ☐ Extremity amputation

☐ Knows appropriate standards of care that health providers should provide

☐ Seeks medical attention in response to symptoms of complications

☐ Knows that complications are multifactorial but that diabetes control is one factor

General Knowledge

☐ Knows why insulin cannot be taken as a pill

☐ Knows the function and need for glucose metabolism

☐ Knows that cells need glucose inside of them to work

☐ Knows that glucose is the major fuel for cells

☐ Knows that sugars are used by the body for energy

☐ Knows that insulin is necessary for glucose to be used

☐ Knows what the dawn phenomenon[o] is

☐ Aware that smoking causes insulin resistance

☐ Knows that intensive insulin and dietary therapy that maintains glycemic control can delay diabetic vascular complications

☐ Knows that smoking is especially dangerous for people with diabetes because it increases the already high risk for blood-vessel disease

☐ Knows caffeine can raise BG and make recognizing symptoms of low BG difficult

Miscellaneous

☐ Uses mild soap to clean skin

☐ Uses warm (not hot) water to clean skin

☐ Uses a non-oil-based moisturizing lotion for skin

☐ Uses sunscreen when in the sun

☐ Has a clearly visible medic alert indicating s/he has diabetes

☐ Knows how to get help when needed

☐ Informs gym teachers and coaches of diabetes

☐ Informs gym teachers and coaches of need for exercise snacks

- ☐ Gym teacher and coaches are prepared to treat hypoglycemia
- ☐ Visits physician at least quarterly
- ☐ Knows that puberty/menses may be delayed in diabetics, especially in poorly controlled diabetics
- ☐ Knows that menstrual irregularities are more common in poorly controlled diabetics
- ☐ Knows that diabetes may be more difficult to control while taking birth control pills
- ☐ Knows that pregnancy for women with diabetes requires an unusually disciplined regimen
- ☐ Knows most infants of mothers with diabetes will not have diabetes

Areas Not Covered

- Interactions with health professionals
- Social aspects (e.g., sleep-overs at friend's house, parties, etc.)
- Cultural aspects of care/education
- Pregnancy (e.g., teen pregnancy)
- Perioperative situations
- Dealing with managed health care and insurance coverage

[a]From ADA[13(p37)] and Eli Lilly and Company, 1997, PA 6662 AMP (information leaflet included with Humalog insulin vials) and ADA, 2006 resource guide: A supplement to diabetes forecast (Insulin section), retrieved May 31, 2006, from http://www.diabetes.org/diabetes-forecast/resource-guide.jsp, but see also American Association of Clinical Endocrinologists[22] for alternative actions:

INSULIN	ONSET (h)	PEAK (h)	DURATION (h)
Animal			
Regular	½–2	3–4	4–8
NPH	4–6	8–14	16–24
Lente	4–6	8–14	16–24
Ultralente	8–14	Minimal	24–36
Human			
lispro/Humalog/aspart/Novolog	≤ ¼*	½–2	2–4*
Regular	½–1	2–3	3–6
NPH	2–4	4–10	10–18
Lente	3–4	4–12	12–20
Ultralente	6–10	None	18–30
glargine/Lantus	1-4	None	20-24

*Recently there has been some information suggesting that lispro does not get into the blood and does not get out as quickly as was once thought.[96]

[b]It is believed that consuming 60% or more of calories from carbohydrate would lead to increased glucose levels following a meal, but, the ADA recommends individualization, so, this task might be to follow the dietitian's recommendations when those are available.

[c]The concern has historically been that concentrated sweets are absorbed more rapidly into the blood stream than starches (i.e., carbohydrate from non-sucrose sources, e.g., breads, fruits, vegetables, cereals, grains); however, research does not substantiate this, therefore, this item may not be applicable.

[d]Drinking on an empty stomach can lead to low blood sugar.

[e]One equivalent = 1 oz of liquor; 1.5 oz of distilled beverage; 4 oz of wine; or 12 oz of beer.

[f]Because of the possibility of alcohol-induced hypoglycemia (due to alcohol being metabolized before food due to its toxicity and its inability to be converted into glucose) no food should be omitted.

[g]A pre-exercise snack (e.g., 15g CHO for 30 minutes or less of exercise, 20-30g CHO for 30-60 minutes of exercise, and continuous CHO replacement [e.g., sucking a hard candy, etc.] for exercise longer than 60 minutes) is suggested if BG is 100-120 mg/dL or if more than 90 minutes have passed since the last meal.

[h]Max HR reserve = 220 – age; target HR = Max HR reserve * [60-85%].

[i]E.g., exercise decreases risk for heart disease through cardiovascular conditioning, reduces cholesterol, increases HDL, increases insulin sensitivity, helps control hypertension, reduces stress, and aids in weight management.

[j]E.g., paleness, sweating, increased heart rate, palpitations, hunger, numbness or tingling in arms and hands, shakiness, inability to concentrate, confusion, slurred speech, irrational/uncontrolled behavior, slowed reaction time, vision changes/blurriness, extreme fatigue, disorientation, unconsciousness, inability to awake from sleep, tingling sensations around mouth, headache, clumsy or jerky movements, and seizures.

[k]Symptoms include: excessive urination, excessive thirst, blurred vision, excessive hunger, weakness, depression, sluggishness, headache, nausea, vomiting, abdominal discomfort, inability to catch his/her breath, and hyperventilation.

[l]Test results are usually provided in terms of Negative, Trace, Small, Moderate or Large.

[m]Stress hormones increase the production of glucose; if activity is not greatly increased, hyperglycemia may result, whereas, if activity is greatly increased, hypoglycemia may result (due to a greater sensitivity of cells to receive glucose during stress).

[n]E.g., extra insulin, extra syringes, fast-acting carbohydrate, snacks, glucose meter and supplies, glucagon emergency kit, prescription for syringes, medical ID, prescriptions for medications, name of health care professional at destination, etc. A directory of English-speaking doctors is available through the International Association for Medical Assistance to Travellers at http://www.iamat.org/ or 716-754-4883.

[o]The dawn phenomenon is an increase in glucose levels and need for insulin during the pre-breakfast hours.